

**Capital gains: parental perceptions on the family
and social lives of deaf children and young people
in Scotland**

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degree of Doctor of Education

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Declaration

- I have composed this thesis
- The thesis is my own work
- The thesis has not been submitted for any other degree or professional qualification except as specified

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ABSTRACT OF THESIS

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It is known that the educational and social development of all children and young people are affected by the quality of communication within the family and by participation in social life and in activities outwith school. Although deaf children tend to under-achieve educationally and to experience marginalisation within mainstream groups, relatively little research has been located within family and out-of-school domains.

This thesis interrogates data which were collected as part of a national questionnaire-based survey of parents of deaf children in Scotland. Quantitative and qualitative analyses of responses to closed and open questions illuminate parental perspectives on the extent to which deafness-related issues influenced: the quality of communication between their deaf children and family members; levels of friendships with both deaf and hearing peers; the amount and nature of their children's participation in cultural and structured social activities; and parental facilitation of their adolescent deaf children's independence.

Although the majority of respondents indicated no, or minimal, disadvantages, a sizeable minority reported specific linguistic and social barriers which influenced key relationships and, in the case of activities, precipitated marginalising experiences. Whilst some clear patterns are revealed, such as a correlation with level of hearing loss and, in terms of parent/child quality of communication, with the hearing status of parents, there was a persistent level of unexplained diversity among those experiencing linguistic barriers.

Limitations to the data restrict the generalisability of findings, although these have import in themselves. In addition, new knowledge is derived from the application of symbolic capital as a heuristic lens. Evidence of the diversity of family communication and 'visitorship' experiences are viewed in the context of linguistic access strategy choices emanating from the complexity of each deaf child's habitus. Indications of differences between children of deaf and hearing parents, in terms of the balance of linguistic benefits and disadvantages, are considered in the context of social and cultural capital which is accumulated through access to alternative deaf and hearing networks.

It is posited that, in order for deaf children to be enabled to realise their highly individual linguistic potential, and to optimise their accumulation of cultural and social capital, there is a need to address the imbalance within the linguistic spectrum of assessments and resources provided by specialist educational services. It is further argued that this should be within the context of a positive conceptualisation of deafness, and a holistic approach to assessment and service provision.

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Introduction

I have worked with deaf children and young people for over twenty years in a number of different professional roles within both social work and education sectors. This background provided me with personal insight into some of the specific challenges faced by deaf people of all ages and their families, and stimulated an interest in furthering the evidence base which informs relevant policy and service development.

Subsequent employment as a research associate in the Achievements of Deaf Pupils in Scotland (ADPS) project presented a unique opportunity to contribute to this body of knowledge. A specific responsibility for the development of the ADPS Family Survey emanated, at least in part, from a particular interest in collaborative work with parents of deaf children, and a belief that their perspectives have epistemological importance within the field of deaf education. This thesis is based on data from the Family Survey which illuminates parental views on key aspects of their deaf children's family and social lives. It uses the theoretical concept of symbolic capital as a lens through which the analysed data is viewed.

Chapter one sets the scene by reviewing the body of academic literature relating to relevant aspects of deaf children's home and social life, including potential impact on the outcomes of educational achievement and mental health. This substantive detail is situated in the context of an explanation of the relevance of the application of symbolic capital, with particular reference to linguistic, cultural and social capital.

Chapter two begins by setting out the research questions addressed by this thesis. It goes on to describe the collaborative processes involved in the development of the Family Survey: the research design; the piloting of research instrument; the distribution of questionnaires, and the chase-up of responses. The final section provides details of the actual response and an overview of the data

analysis process, further information about which is given at relevant places in subsequent chapters.

Chapter three aims to establish the extent to which the sample is representative of key comparator populations. Selected data on the deaf children of respondents is compared, as far as possible, with data on all Scottish deaf children, whilst socio-economic data on respondent parents is compared with comparator groups within the total population of Scottish parents.

The first section of chapter four describes details of the first language of the deaf children of respondents, as a precursor to the presentation of findings relating to the quality of communication between the deaf children and members of the inner and outer circles of their families. As the early years are so significant to language development, the chapter ends with a sub-section which focuses on the situation of pre-school children.

Chapter five presents an analysis of data relating to: deaf children's friendship patterns; their participation in social and cultural activities and indicators of parental encouragement of independence in their deaf children's adolescent years.

Limitations to the generalisability of the data are explicated in chapter six, followed by the application of a symbolic capital framework to main findings in each section. The final chapter offers two models which provide frameworks within which subsequently described implications for policy, practice and further research can be considered.

Deaf, deaf or d/Deaf

Within literature relating to the field of Deaf Studies, there is an accepted convention that a capital 'D' is used for the word 'Deaf' when referring to those whose first or preferred language is a sign language such as British Sign Language (BSL), and who regard themselves as a cultural-linguistic minority. This convention is used in this thesis when it is unequivocally clear that the description is appropriate. However, the nature of the data is such that situations are rarely unequivocal and therefore, in the majority of cases, the lower case 'd', as in 'deaf', is used. Exceptionally, in chapter 7, there are particular references to situations where Deaf people are clearly included within a broader group. In these cases the term 'd/Deaf' is employed.

Chapter One: Literature Review

It is known that parental involvement in their child's education is a strong predictor of educational success (Bastiani, 2000; Moeller, 2000; Munn, 1993) and that the quality of an individual's social relationships and networks can have a significant impact on disadvantage, educational outcomes and well-being (Allan, Forthcoming). Yet research relating to under-achievement and psycho-social issues among deaf school pupils usually focuses on educational or, more rarely, clinical environments; relatively little research has been done on deaf pupils' lives outside of school, including relationships with family and participation in activities outside of school. In this chapter I will review what is known, using the theoretical construct of symbolic capital as a lens through which to explore the literature.

An initial introduction to relevant aspects of symbolic capital is followed by exploration of substantive literature relating to the experiences of deaf children. Problematic outcomes of relatively low educational achievement and socio-emotional issues are set within an exploration of factors likely to affect these outcomes within the realms of family life, friendships and extra-curricular activities. In a final section, I apply a framework of symbolic capital to key issues which have been raised throughout the chapter.

The relevance of 'symbolic capital'

Hearing children usually acquire spoken language naturally, and this provides the basis for the development of both spoken and written communication. For deaf children, the process of acquiring spoken language is more challenging.

Simplistically speaking, the more deaf the child, the less possibility there is that he or she will be able to acquire spoken language in the same way, and at the same rate, that hearing children acquire spoken language. As over 95% of deaf

children are born to hearing parents who have had little or no previous experience of deafness, most parents face challenges in adapting their family lives to ensure that their deaf children are not disadvantaged by barriers to language acquisition and development (Marschark, 2007). This general statement applies whether or not they decide to introduce a signed language into the linguistic repertoire of the family, and whether or not they facilitate their child's contact with other deaf people.

Bourdieu developed the metaphor of 'symbolic capital' to aid understanding of the source of inequalities in educational attainment of pupils and students from different social class backgrounds. He sub-divided the concept into various types, the two major categories being 'social capital' and 'cultural capital' (Bourdieu, 1986). 'Linguistic capital' is specified as a further subdivision of cultural capital, and is deemed to be at the heart of a child's 'habitus' – their 'complex, internalised core from which everyday experiences emanate' (Reay, 2004) - and which is their wherewithal for engaging and prospering, in the terms of the dominant culture within their society (Bourdieu & Passeron, 1977). An individual habitus is described as a complex synthesis of external, structural influences and internal, individual aptitudes and 'appropriating capacities' (Bourdieu, 1986). The influence of the family, as the location of 'primary pedagogical work', is seen as pivotal (Bourdieu & Passeron, 1977).

A central focus of the theory of symbolic capital is the insidious effect of unequal power relationships within society, which gives legitimacy to the essentially arbitrary cultural values underpinning and creating the content of education in its broadest sense. It is not the intention, in this study, to explore or challenge the provenance of the structures creating and maintaining dominant cultural values.

However, in taking as a given the current hierarchy of valorised knowledge and aesthetics within the educational system, I do not mean to signify a disrespect for Bourdieu's central thesis. Rather, the study is rooted in the assumption that, however unequal may be the chances of children from different social classes achieving optimal distinction culturally, socially and linguistically, those of deaf children can

be additionally, and distinctively, suppressed throughout the class spectrum. I suggest that key aspects of the concepts of social, cultural and linguistic capital are pertinent; in particular, that language and communication is pivotal to the development of capacity to achieve educational and psycho-social prosperity, both within and outwith the school environment.

Thus, if one applies the concept of symbolic capital to the situation of deaf children, it seems reasonable to posit that linguistic restrictions to the ‘primary pedagogical work’ undertaken by families of deaf children, and to the ‘appropriating capacity’ of language within a deaf child’s habitus, will impact on the accumulation of both social and cultural capital. Accepting that the theoretical terms used are contested in terms of empirical evidence (McGonigal et al., 2007), my intention is to use them in a heuristic way for exploration of both contextual literature and findings. In this sense the way that symbolic capital is applied here is, as Morrow (1999:760) states:

‘...a descriptive construct...a useful heuristic device, a tool with which to examine social processes and practices.’

Cultural capital and social capital

‘...the best hidden and socially most determinant educational investment...(is) the domestic transmission of cultural capital’
(Bourdieu, 1986:244)

Cultural capital is concerned with the accumulation of valued cultural knowledge, however arbitrarily determined by dominant groups within society. Bourdieu’s emphasis on the prime role of the family in the inculcation of cultural capital is borne out, in its ‘institutionalised state’, by evidence that the quality and quantity of parental ‘investment’ at home significantly aids educational achievements for all children (Bastiani, 2000; Heineman-Gosschalk & Webster, 2003; Munn, 1993). The role of language and communication is fundamental in the transmission of valorised knowledge by families. In this study, the concept will be

particularly applied to family communication and to deaf children's participation in educational and cultural activity outside of school.

Coleman (1994:300) describes **social capital** as an accumulation of:

‘... the set of resources that inhere in family relations and in community social organisation and that are useful for the cognitive or social development of a child or young person’.

Significant among these resources are undoubtedly language and communication: as the basis for forming and maintaining relationships, and in their interdependent relationships with cognitive development.

Social capital is therefore a particularly appropriate heuristic device to apply to the relationship and activity-based focus of this study. It will be used, in Schuller, Baron and Field's (2000:2) terms:

‘(in) its capacity to open up issues rather than to provide definitive answers’

Before applying the concepts of both social and cultural capital to the situation of deaf children, substantive literature will be reviewed in relevant aspects of the family and social life of deaf children and young people.

Families and deaf children's achievements

Deaf children are born into families across the spectrum of social class, and there is some evidence that socio-economic factors impact on deaf children's achievement (Marschark, 2007). It is also known that, as with hearing children, parental ‘investment’ in their deaf child's education has an impact on school attainment. Calderon and Greenburg (1993) found that consistent support from families led to higher educational achievement of deaf pupils, significant specific

factors being: quality of family interaction; level of parental expectations, and level of parental acceptance of, and adaptation to, deafness. Alfazi-Nomadi's (1995) survey of deaf educators and classroom teachers in Kansas indicated that parental support was one of the most significant factors relating to confidence and self esteem of pupils in mainstream educational programmes, and individual narratives of high-achieving former pupils consistently rate parental commitment and support as having been highly influential in their academic success (Grimes, 2006; Powers, 2006). Toscano, McKee and Lepoutre's (2002) in-depth study of high-achieving deaf college students' retrospective views of their literacy development demonstrated that, in addition to parental commitment, support and high expectations, the quality of communication between themselves and their parents was fundamental to their achievement, whatever the language/language mode.

However, there is strong evidence that total populations of deaf pupils, including that of Scotland, underachieve educationally, compared to total populations of their hearing peers, and have done so historically and persistently (Karchmer & Mitchell, 2003; Powers, 2002; Powers, Gregory, & Thoutenhoofd, 1998; Thoutenhoofd, 2006). As deaf children are known to perform similarly to hearing pupils in language-independent intelligence tests (MacSweeney, 1999; Marschark, 2006; Marschark, Langs, & Albertini, 2002), it is clear that there is something restricting the 'linguistic capital' of deaf children, over and above social class differences, which is influential in their underachievement generally.

The fact that the early years are critical in the development of language (Sorace, 2006) and that language and cognitive development are symbiotically related, means that parents of deaf children are in a key position to address deaf children's development in both areas, particularly in pre-school years. Indeed, Marschark's (2007:5) review of relevant research concludes that:

'Effective parent-child communication early on is easily the best predictor of success in virtually all areas of deaf children's development, including academic achievement.'

More specifically, there is some evidence that the quality of communication between parent/deaf child and deaf child/sibling dyads is important not only in language development, but also in development of autonomy, initiative and reasoning, and other transferable skills from complex and creative play (Heineman-Gosschalk & Webster, 2003; Woolfe, Want, & Siegal, 2003).

As it is known that the social experiences of deaf children are more concentrated within the family than those of hearing children (Marschark, 2007), the socialising function of the family is particularly significant – equipping deaf children with social skills for making relationships in a wider context.

However, as already noted, adapting their family lives to fully include their deaf children, and to facilitate their acquisition of language, is a major challenge for most parents.

Evidence of everyday communication challenges within families

Families with hearing parents

Despite developments in research, legislation, policy, linguistics, technology and services, hearing parents of deaf children continue to raise language and communication as highly problematic when describing the impact of having a deaf child in the family (Beazley & Moore, 1995; Eriks-Brophy et al., 2007; Gregory, Bishop, & Sheldon, 1995; Marschark, 2007; Minchholm, Shepherd, White, Hill, & Lund, 2003). They are faced with the reality of the fact that their child does not have full access to the language used by their family in the everyday communication - ‘a situation likely to affect learning in a variety of domains’(Marschark, 2007:188). One major effect is that of restricting the kind of incidental learning which informs both general and specific, curriculum-related knowledge (Gregory, 1998; Marschark, 2007). It has also been shown that hearing parents tend to use more concrete, less

abstract language with deaf children – language which tends to contain less information than that used with hearing children. This has a direct impact on the extent to which deaf children are enabled to acquire and manipulate facts and knowledge (Marschark, 2007; Meadow, 1980).

As parents tend to deal with the fact that their child does not have full access to the main language of the family by distilling communication with their deaf child to key information, this can also affect the child's social inclusion in the family.

Thus, Gregory et al. (1995) found that it was common for young deaf people to miss out on a lot of information by not 'catching the moment' in the kind of quick-fire conversations which are part of everyday family life; consequently 39 out of the 49 young deaf people who talked about access to family events in her study said that they had not been informed about significant family occasions. For example, in relation to one of these young deaf people, they stated that,

'despite the efforts made within the family, communication was difficult and she remained excluded except when specific efforts were made to tell her things.',
(Gregory et al., 1995:37)

Group discussions generally are notoriously difficult for deaf people to follow and, as group discussions are a regular feature of family life, they can be a regular cause of social as well as information exclusion. The vast majority of the 82 young people and their parents in Gregory et al.'s study reported concerns over linguistic access to group situations. Young people reported consequent feelings of frustration and isolation, exemplified by the following quote from a 19-year-old participant:

'...a family party is not ideal for me. I never talk, I just listen. People say, "Hello", "How are you?" or "'Sunday dinner – OK?" that's all'
(Gregory et al., 1995:31)

Similarly, young deaf people in Skelton and Valentine's (2002) research sample reported feelings of frustration at being excluded from group communication in everyday family experiences such as meals and family visits, as well as significant events such as weddings and parties. Withdrawing themselves to other rooms, or to solitary activities was common.

Communication is two-way, and it can also be a struggle for deaf children and young people to make themselves easily understood in contributions to spoken family conversations. In their study of 35 families in the North West of England, Minchholm et al. (2003:99) found that the vast majority (86%) reported that 'there were times when members of the family could not understand the child's attempts at communicating.'

Interestingly, in Gregory et al.'s (1995) study, parents tended overall to be more positive in their evaluation of the quality of communication between their deaf child and the rest of the family than were the deaf young people themselves.

In terms of communication with individual family members, a number of studies have confirmed that mothers tend to spend more time than fathers working on language and communication development with their deaf child, and to take a lead role within the family (Eriks-Brophy et al., 2007; Gregory et al., 1995; Kluwin & Gaustad, 1991, 1994; Skelton & Valentine, 2002). Therefore it is not surprising that the studies demonstrated that deaf children tend to be able to communicate better with their mothers than with other members of the family. Toscano, McKee and Lepoutre (2002) found evidence that mothers of their sample of high-achieving deaf college students had tended to take the lead in promoting communication between the deaf child and the family as they were growing up.

Although the relatively dominant role of the mother means that fathers tend to play a lesser part, fathers in Eriks-Brophy's (2007) admittedly small and socio-economically skewed sample, reported that practicalities, rather than lack of willingness, restricted their involvement. However, many of the young deaf people in

Gregory's and in Skelton & Valentine's larger samples reported specific concerns over difficulties in communicating with their fathers and Meadow (1980) also cites evidence that fathers tended to interact less frequently than mothers.

This is all in the context of evidence which suggests that there are maternal/paternal differences in style and quality of communication within all-hearing families. Shepherd and Galloway's (2003) review of literature indicated that, whilst the evidence ostensibly points to poorer, more 'challenging' quality of communication in the father/child dyad, in fact, the father's less sensitive styles have sometimes been shown to be developmentally beneficial for the child. They also point out that the differences may be transcended by the complex nexus of other individual, social and economic influences within and outwith the family.

Returning to the situation of hearing families with deaf children, some research has shown that this maternal responsibility can extend to the adoption of more of a teaching role with their deaf child than would normally be the case with hearing children (Wood, 1991), thus changing the dynamic of the parent-child relationship. Eriks-Brophy et al. (2007:26) found that there were often particular stresses involved when mothers became their deaf child's 'primary speech and language teacher'. A number of the 24 parents in their study reported regret that the language teaching role had outbalanced the natural communication involved in the parental role. Whilst Galloway and Woll (1994) suggest that this greater control can be seen as an appropriate adjustment to their assessment of their child's language skills, there is also evidence that hearing parents tend to take on a more didactic role when helping their deaf children to read, thus encouraging a dependence which can be a hindrance to the development of independent learning skills (Marschark, 2007; Meadow, 1980). Some of the young deaf people in Skelton & Valentine's (2002) study indicated that an overly didactic approach can cause over-dependence, particularly problematic at transition to independent living; although, in a later study they emphasise that family protectiveness can be seen more positively where it supports the building of self-esteem and confidence in making transitions from school to work and from home to independent living (Valentine & Skelton, 2007).

Hearing siblings have a unique place in the social lives of deaf children, sometimes communicating better with their deaf sibling than do other members of the family. Deaf young people in Gregory et al.'s (1995:40) study rated the quality of communication with their siblings as second only to that with mothers, and that there could be a 'special sort of understanding' between them. Particular pressures on this relationship, however, arise from the two sources: the fact that parents may devote a disproportional amount of attention to their deaf child, and the fact that hearing siblings may find that they are expected to take on the role of mediation and translation between their deaf sibling and hearing friends. While the positive aspects of this special relationship can be highly valued by the deaf member of the family (Eriks-Brophy et al., 2007; Gregory et al., 1995) the imbalance of parental attention can cause resentment (Archbold, Lutman, Gregory, O'Neill, & Nikolopoulos, 2002; Marschark, 2007; Skelton & Valentine, 2002) and the mediation/translation role can lead to a dependency which can impact on deaf children's independent social skills (Marschark, 2007)

The close relationship which grandparents often have with their grandchildren can be particularly valued by deaf children and supportive to their parents. Beazley and Moore (1995) exemplify this with one case where a hard of hearing grandfather persuaded his granddaughter to wear her hearing aids by normalising the experience. However, there is evidence that many grandparents can find the communication barrier too challenging to overcome and this compromises the potential for the uniquely valuable relationship. Consequently, Gregory et al. (1995:40) found that the lack of communication between a significant proportion of young people in the sample and grandparents was 'most keenly felt' by the young deaf interviewees and their parents.

Awkwardness in making language and communication adjustments can also apply to other members of extended family and close friends. Most studies so far cited have reported that extended family are usually great sources of ongoing support for parents of deaf children, and Marschark (2007) notes that parents who get support

from extended family and friends are most likely to adjust well to having a deaf child. Therefore, as is the case with grandparents, where other family members have difficulties in relating to the deaf child, parents can feel particularly bereft of support. In fact, lack of support from extended family was cited by Eriks-Brophy et al. (2007) as one of the most frequent barriers to their child's integration, whereas good communication with extended family was a consistent feature of reports from high-achieving college students in Toscano et al.'s (2002) study.

The situation can have particular complexities where the spoken language at home is not the main language of the country, in the case of the UK, English. The early interventions of specialist professionals can mean that hearing families who speak minority languages at home are expected to support greater access to spoken English for their deaf child than that provided to hearing siblings. In this context, Mahon (2003) highlights the problematic fractured communication which can arise when one or the other parent's own grasp of English is limited.

Therefore, the key part which families play in nurturing the cognitive, linguistic and social development of deaf children can be affected, to varying extents, by barriers resulting from language and communication restrictions in both one-to-one and group family situations – barriers which can impact on educational achievement and on the deaf child's sense of membership and belonging.

Deaf parents

The problematic issues so far described emanate from the fact that the families of the vast majority of deaf children are hearing, and so the deaf child is most often surrounded by a challenging language and communication environment. Where parents are deaf, they are already prepared for the possibility that their child will be deaf and the language and communication environment is more likely to be geared towards the linguistic, social and practical situations of deaf people. Therefore many of the communication barriers described above will not apply (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003). Deaf parent/deaf child discussions are likely to be richer in linguistic content, and this probably explains the

fact that young deaf children of deaf parents have been shown to have a more sophisticated understanding of specific characteristics and capabilities of other human beings than deaf children of hearing parents (Marschark, 2007). Vaccari and Marschark's (1997) literature review showed that parents whose communication with their deaf child is most fluent and natural are less likely to allow didactic communication to dominate the relationship with their child, and therefore can be seen to apply to deaf parents.

It has been assumed by some researchers in the past that such factors have led to deaf children of deaf parents achieving higher educationally than deaf children of hearing parents. However, Marschark (2007) points out that evidence for this is only correlational and that early access to a fluent language is the causal factor, rather than hearing status of parents, regardless of whether the language is a spoken or signed language. This is borne out by the diversity of language and communication modes used by the predominantly hearing parents in both Toscano et al.'s (2002) and Powers' (2006) studies of high-achieving deaf post-school students. The main language used in many homes of deaf parents is a signed language, such as, in Britain, British Sign Language (BSL).

The place of sign language

Despite decades of research into language and communication approaches aiming to level the attainment gap between deaf and hearing children (including studies into early intervention work with families) there is no robust evidence that focusing solely on spoken language will fulfil this goal (Marschark & Spencer, 2006; Powers, 2002; Powers et al., 1998; Young et al., 2006). In fact, rather than showing that the use of a sign language is detrimental to linguistic and cognitive development, it has been demonstrated that children who use sign language early tend to do better academically than those who don't (Calderon & Greenberg, 1993; Marschark, 2007). However, the prevailing discourse equates deafness and sign language with deficiency – often implicitly rather than explicitly. My own experience as a deaf

education professional equates with Brennan's (1999:3) observation that:

'In practice and in attitude, the notion that BSL is somehow not a 'proper' language is built into the everyday parlance of many professionals working with deaf children.'

Similarly, Corker (1998:88) posits that the framing of sign language as a 'need', rather than a linguistic right, is built into the legislative and policy fabric of educational provision, mitigating against linguistic choice at the level of professional intervention.

'Children do not *choose* to learn sign language, they are assessed in order to make decisions about whether they *need* to use it... If the child has enough residual hearing, they will not, as a rule, be assessed as needing sign language because they will be seen as having the potential to communicate 'in the hearing way'.

This makes it unlikely that sign language is accorded equal status in the advice, assessments and services provided to parents. There is evidence that advice from professionals can be biased, restrictive and geographically variable, in terms both of language and communication choices and of conceptualisation of deafness (Beazley & Moore, 1995; Gregory et al., 1995; Young et al., 2006).

In 2006, Young et al. (2006:323) noted that the preceding three decades of research had consistently highlighted parental reports that professional services had limited the range of language and communication choices available – within a context of concerns about the attitudes of professionals towards deafness itself. A 'medical' or 'deficit' approach to deafness implies exclusion of BSL - its use being intrinsic to a conceptualisation of deafness as a cultural-linguistic alternative:

'...parents report encountering predominantly medical models of deafness or deficit approaches in their early dealings with professional services only to discover later cultural-linguistic models and alternative approaches to understanding the social identity of their children.'

In the following year, Young and Tattersall (2007:219) pointed

out that, while the Universal Newborn Hearing Screening (UNHS) programme was not established on the basis of exclusively promoting oral/aural trajectories, in fact parental perceptions indicated that :

‘The normal or near-normal possibilities held out for deaf children are almost exclusively defined in terms of speech and hearing and according to the standard of what is a normally developing hearing child’.

In Scotland, recent research concluded that few services provide rich environments in both signed and spoken languages, that it is not universally accepted that both are needed, and that the breadth of linguistic options available to deaf children and their families may be determined more by the region in which they are educated than by their specific linguistic requirements (Grimes, 2008; Grimes, Thoutenhoofd, & Byrne, 2007). Data collected by ADPS in 2001 showed the paucity of BSL assessments undertaken with preschool deaf children compared to those in spoken English (table 1.1).

Table 1.1: Spoken English and BSL assessments undertaken with deaf preschool children in Scotland, 2001 (n=179)*

| | Formal | Informal | Total | Not known |
|---|---------------|-----------------|--------------|------------------|
| Spoken English productive skills | 22 | 64 | 86 | 3 |
| Spoken English receptive skills | 19 | 59 | 78 | 10 |
| BSL productive skills | 4 | 8 | 12 | 2 |
| BSL receptive skills | 5 | 7 | 12 | 1 |

*Source, (Grimes, 2008:43)

The lack of formal BSL assessments is not surprising when one considers that, by 2007, there were still just 2 people in Scotland trained to use the only formal BSL Production test available, and just 8 packs of the only BSL receptive skills assessments available had been sold in Scotland since the test was published in 1999 (out of several hundred sold throughout the rest of the UK) (Grimes, 2008). Furthermore, the same study reported that it was common for Scottish local authorities to fund staff to attend the only accredited university-level training in early years and deafness, which addresses spoken language only and does not include information about early sign language development.

Undoubtedly, early diagnosis of deafness, and the possibility of cochlear implantation for infants of as young as a few months old, are making significant differences to the potential for development of spoken language and the consequent potential for overcoming some of the barriers experienced within hearing families. Archbold et al. (2002) found that 8 of the 30 parents in their study sample reported that communication had improved between grandparents and their deaf grandchild after implantation. In a later study, Archbold, Sach, O'Neill, Lutman and Gregory (2008) found that over 80% of 101 respondent parents reported that their deaf children had positive relationships with their implanted grandchildren. However, there are a number of areas of caution in predicting outcomes. Few studies have rigorously assessed the ability of implanted children to use spoken language in their day-to-day lives outside of the clinical setting, and, while there is evidence of a positive impact of early cochlear implantation on attainment (Fortnum, Stacey, Barton, & Summerfield, 2007; Thoutenhoofd, 2006), there is still evidence of a shortfall in relation to the quality of access to informal and formal learning situations and to the attainment levels of hearing children (Marschark, Rhoten, & Fabich, 2007; Vermeulen, van Bon, Shreuder, Knoors, & Snik, 2007). Also, there has been shown to be diversity in linguistic aptitude and preferences among implanted infants and children and, for some implanted children, sign language will be the language which most exploits their linguistic potential. Where this is not identified until school-age, vital language acquisition time will have been lost (Leigh, 2008).

Furthermore, children with cochlear implants still experience deafness, albeit to a lesser extent than prior to the implant, and there is evidence that children with moderate mild hearing losses can have linguistic access problems in some situations, particularly where acoustic conditions are poor and/or where the environment is noisy (Antia, Stinson, & Gaustad, 2002; Goldberg & Richburg, 2004). This can lead to experiences of loneliness and isolation (Bess, Dodd-Murphy, & Parker, 1998; Goldberg & Richburg, 2004; Kent, 2003). There is also evidence that relatively mild hearing loss levels can affect language and literacy development (Bess et al., 1998; Moeller, Tomblin, Yoshinaga-Itano, Connor, & Jerger, 2007). Bess et al.'s (1998)

study found a connection between particularly minimal hearing loss levels (auditory thresholds of 16-25 decibels) among primary age children and difficulties with language, communication and reading.

Parents rely heavily on professionals for advice on language and communication (Beazley & Moore, 1995; Department for Education and Science, 2006) and therefore, despite the benefits of advances in early diagnosis and cochlear implantation, it remains a cause for concern that they are rarely given a well-resourced sign-inclusive spectrum of linguistic information and services which will best enable them to harness their child's linguistic potential in their 'primary pedagogical work' with their deaf child. This is in the context of evidence that caseload prioritisation within specialist services is most likely to be on the basis of narrow, impairment-related issues, rather than on more holistic criteria (Rodd & Young, 2009). Knoors (2007) refers to the need for a well-resourced 'no exclusion' spectrum of language and communication options, to enable the nurturing of individual linguistic aptitudes and abilities through ongoing assessments and quality services. However, it is clear that this is not the norm.

Next to family, the weaving of the nexus of relationships which anchor children and young people in the world, and give them a sense of belonging, is provided by the formation and maintenance of peer friendships.

Friendships

Although this study focuses on life outside of school, there is a particular overlap in relation to friendships, as it is so common for friendship networks to be formed at school.

A policy and legislation trend towards inclusion of children with 'additional support needs' in mainstream education (Great Britain, 1980; Scottish Parliament, 2000) has impacted the number of deaf peers with whom deaf pupils come into direct

contact. In 1983 there were 13 schools for deaf children in Scotland; by 1994 there were 9 (BATOD, 1984, 1995) and by 2001 there were only five, two of which had very small numbers (ADPS unpublished data). In the early eighties, it became increasingly common for local authorities to provide distinct units within schools which provided a base for some discrete teaching with deaf individuals and groups as well as a place of social contact for deaf pupils. However, the main drive has been to presume full inclusion into mainstream as a default position, now enshrined in law (Scottish Parliament, 2000), thus increasingly making it less likely that deaf pupils will come into regular contact with significant numbers of other deaf pupils. It is not uncommon now for a deaf child to be the only deaf pupil in a class or even a whole school.

Gregory et al.'s (1995) study followed up deaf young people who had started school in the mid-seventies, when most deaf children attended separate schools, the majority of which were residential. Therefore, the school-friends of most deaf pupils were mostly, if not all, deaf. She found that the majority of the 34 young deaf respondents who discussed relations with hearing peers reported that they had difficulties in social groups of hearing friends generally, regardless of type of educational placement or preferred language/mode of communication. However, the majority of her total sample also indicated that they had a rich and varied social life among deaf peers. Whether or not this can be seen as an equally valuable alternative to the potential for individual relationships and networks among hearing peers has been a contested issue in deaf education even before the Education (Scotland) Act, 1980, first enshrined in legislation the concept of mainstream integration in Scotland.

An underlying assumption of the 'inclusion agenda' has been that separate schooling is intrinsically isolating and socially limiting, and problematises the pupil rather than the system (Ainscow, 1991). Whilst a key motivating force behind inclusion policies (and parental support for them) has been the assumption that the standard of education would be higher in mainstream schools, the agenda also embodies an assumption that mainstream, non-deaf peers represent normality, and that making one's way in such an environment will redress the social and academic

imbalance caused by the deficit of deafness. The geographical distance that children have had to travel to attend special schools for deaf children has been a bone of contention – including major concerns about access to local networks of hearing peers.

In this case, it could be construed that the perception of the young people in Gregory et al.'s (1995) study who reported being happy with their social lives were either simply restricted by knowing no better, or were making the best of their limited situations. Certainly there was a discrepancy between the young people's own reports of their friendship patterns and that of their parents; parents being significantly and consistently more negative than their deaf offspring. They were more likely to see their children as having fewer, less stable friendships than the young people themselves described. However, Gregory et al. construed that this probably indicated a different conception of the term 'friendship'.

It is also possible that parents in this study problematised the notion of deaf friendships because of the connotation of deviation from the norm, perhaps indicated by the discrepancy between high number of young people who reported attendance at a deaf club, and the low number reported by parents, suggesting a lack of willingness on the part of parents to admit their children's strong connection to another community of which they were not part.

On the other hand, an alternative view of deaf social networks is predicated on a different conceptualisation of deafness, where deafness is viewed in linguistic difference terms rather than in medical terms: a deaf baby seen as a 'little linguist' (Brennan, 1999) rather than, in extremis, a 'pair of defective ears' to be 'cured' (comment reported to me by a specialist paediatrician in relation to attitudes of her colleagues). Deaf writers themselves have reported a different sense of self: a 'different centre' (Padden & Humphries, 1988) where deaf social networks are viewed as a positive alternative to be seen as a deaf young person's right – rather than a brave 'making the best of things' safety net (Deaf Ex-Mainstreamers' Group, 2003).

Whether or not this is the case, the ongoing tension between the two conceptualisations of deafness is likely to be a major aspect of deaf pupil experiences in family and social lives; individual struggles with, and resolutions of, these tensions can be taken to be at the very foundation of an individual deaf child or young person's habitus.

Young deaf people have consistently reported more social ease with deaf friends than with hearing friends generally, although most research is focused on educational placement rather than on family situations. In general, there is a link between level of deafness, extent of use of sign language and the number of/desire for deaf friendships (Gregory & Knight, 1998; NDCS, 2008; Stinson & Whitmire, 1992). In some cases, the relative lack of comfort with hearing peers reported by deaf pupils relates to difficulties in keeping up with quick-fire spoken language conversations which hearing young people have (Beazley & Moore, 1995; Gregory et al., 1995). As with family group situations, there is also a consequent restriction on much informal and incidental information which hearing people tend to acquire in informal group conversations.

At a deeper level, one respondent in Gregory et al.'s (1995:163) study describing feelings of 'know(ing) I am with my own people' when with deaf peers, again suggesting something more profound than a mere safety net, and some studies have indicated a link between socialising with deaf peers and self esteem: for example, Eriks-Brophy et al. (2007). In fact, contrary to the expectations that educational inclusion would reduce isolation among deaf young people, there is evidence that deaf pupils in mainstream situations can experience an easily overlooked sense of exclusion, resulting in problems with identity, emotional security and starting/maintaining friendships (Marschark, 2007). A UK-based organisation called the Deaf Ex-mainstreamers Group was formed by former pupils who had experienced this sense of exclusion. In their book, 'Between a Rock and Hard Place', one former mainstream pupil describes the profound impact on identity

of being placed in a school environment geared to the characteristics of hearing pupils:

‘The coping mechanism that seems to be common among us DEXies is the borrowed concept of “think-hearing identity”, which DEX uses to explain what it is like for deaf people in deaf oral education, particularly those who are mainstreamed individually. This literally translated into “think-I-am-a-hearing person”. I tried to sing, to act in school plays, to dance and to speak French and Latin, and, to a certain extent I succeeded... These acts were never done on the basis that I was a Deaf person attempting to do hearing activities, but as another hearing person failing to keep up...’
(Deaf Ex-Mainstreamers' Group, 2003:83)

There is evidence that hearing mainstream pupils tend to be less drawn to deaf children as friends and that patterns of interaction tend to be more limited between deaf and hearing friends than between deaf/deaf and hearing/hearing friends.

Capelli et al.'s Canadian (1995) study compared 23 oral/aural deaf children of various hearing loss levels, within an age range of 6 to 12 years, and all of age-appropriate academic standards, with an age and gender-matched sample of 23 hearing children in the same three schools. They found that deaf children were more likely to be rejected by hearing peers, and to have generally lower social status. Bearing in mind the small size of the sample, they also found no correlation between the level of hearing loss (from mild to profound) and level of social status, but did find that the younger children were more likely to be rejected by hearing peers.

Minnet et al.'s (1994) Texas-based research focused on 30 deaf and 30 hearing preschool children in an integrated deaf/hearing centre which provided ‘total communication’ (Sign Supported English) language environments for deaf children in some classrooms and oral/aural environments in others. The sample was split evenly between the two approaches. Researchers found that, when left to their own devices, hearing children demonstrated little interactive play with deaf children and that both deaf and hearing children were much more likely to engage same-hearing-status children in play. They discovered that these phenomena were evident whether the children used sign communication or not.

Also, as previously described for hearing siblings, there can be an additional pressure on hearing friends to take on the role of communicators for group social situations, whether this involves relaying spoken language in some way or translating into a sign language (Eriks-Brophy et al., 2007).

There is inconclusive evidence of the predictability of social skills from preschool to school stages. Although Gregory et al. (1995) found that those assessed as having good social skills at preschool were highly likely to report a rich social life as young adults (regardless of language/communication mode), the early skills of those more lonely later on were diverse enough to make prediction difficult. Capelli et al.'s (1995) findings suggested that deaf children may develop higher levels of social skills, relative to age, as they move through primary-level schooling, although, as noted, the sample was too small to generalise. Furthermore, as the younger and older groups were different children (that is, rather than a longitudinal study of the same children) it may have been the case that the older group was idiosyncratic and/or the differences were the result of general maturation .

The impact of cochlear implantation on social functioning is also inconclusive so far. Archbold et al. (2002) provided evidence that early cochlear implantation can improve the chances for independent relationships with hearing children, but this was confounded by the difficulty in disentangling the effect of the implantation from the general effect of maturation. In a later study, Archbold et al (2008) found that out of 101 parents of implanted deaf children, two thirds reported that their children had been socially isolated prior to implantation, but over 70% reported that their implanted children were making friends easily outside of the family at the time of the study survey (three years after their children's implantation). Meanwhile, while the 25 parents in Bat-Chava and Deignan's (2001) study reported that implantation had improved their children's ability to communicate orally with hearing friends as well as boosting their confidence, they found that a majority still experienced restrictions in these relationships. Over a quarter of the parents in this study volunteered the information that they and their

child put high value on deaf friendships, or that they wished their child to have friendships with deaf peers. Similarly, Archbold et al. (2002) reported that some parents felt that implantation widened the choice of friendships so that their deaf child stood more chance of being comfortable with both deaf and hearing people - although this has not been corroborated by studies seeking the views of the children and young people themselves.

In terms of implications for identity, Wald and Knutson's (2000) small-scale study of implanted and deaf non-implanted adolescents found that, while implanted young people showed a greater preference for hearing identity than the non-implanted group, they indicated a similar inclination towards Deaf/hearing bi-cultural identity. Given the diversity of the deaf pupil population, it does seem to follow that enabling a child as far as possible to be equipped with resources to have the choice of both deaf and hearing friendships is a way forward. This seems to tie in with Knoors' call for a 'no exclusion' policy regarding linguistic options, as mentioned above.

Both Eriks-Brophy (2007) and Gregory et al. (1995) note the fact that parents can act as mediators or facilitators in making and maintaining friendships with both deaf and hearing children, which can be double-edged in creating some degree of dependency, such as that created by parents assuming the responsibility of phoning on behalf of their deaf child (although both authors point out that increased use of texting via mobile phones and emailing may counteract this dependency). Both report particular efforts made by parents in facilitating their deaf children's contacts with other deaf children – something which could involve travelling long distances. On the other hand, Gregory et al. also found evidence of parental denial of their child's apparent deaf community membership, demonstrated by a lack of acceptance of the fact that their son or daughter regularly attended a deaf club.

The possibilities for peer relationships are constantly changing due to developments in a variety of key areas such as: policy and legislation relating to educational inclusion and disability discrimination; technology (including cochlear

implantation); sign linguistics; and service developments - such as meeting opportunities provided by the National Deaf Children's Society. In their respective UK and USA-based literature reviews of deaf children's friendship patterns, both Gregory & Knight (1998) and Marschark (2007) point out the relative paucity of information on the precise nature of deaf children's friendships and call for more detailed study, given the importance of peer relations for personal and social development.

Outwith school, organised visits and activities are key means by which pupils learn informally, as well as formally and maintain social networks through shared interests. Therefore the following subsection focuses on what is known about the participation of deaf children and young people in such pursuits.

Participation in activities outwith school

Families are known to play a significant part in the nurturing of all children's sports talents (Kay, 2000), and participation in extra-curricular activities, such as special interest clubs, sports and other activities, has been recognised as potentially having a positive impact on all children's school experience, social relationships and self-esteem (Stewart & Stinson, 1992). Schwartz (1990) and Stewart & Stinson (1992) have suggested that there is much evidence that, for deaf children in mainstream schools, there is an additional advantage of encouraging the kinds of social skills which can enhance the experience of educational inclusion generally. Similarly, Antia et al. (2002:224) noted that membership in out-of-school clubs and activities,

‘...provides a sense of belonging more consistently than does the classroom or informal groups in school hallways.’

A number of studies have demonstrated the particular place of sport in the lives of some mainstream deaf pupils – sometimes providing them with opportunities to achieve on a more equal footing with hearing peers than is the case

in the academic domain (Eriks-Brophy et al., 2007; Green, 1990; Schwartz, 1990). One parent in Eriks-Brophy et al.'s (2007:18) study described sport as a 'niche that gives some credibility' and another as 'a way in which our son could compete as an equal...Because once they excelled at that, it just carried over into their self-confidence and self-esteem'. It can also be a more motivating forum for efficient communication than the classroom (Farrugia & Austin, 1980). Stewart and Stinson (1992) reported Stinson and Whitmire's findings, in England, that school pupils who were most involved in structured activities, such as sport, outside of school, tended to also have more informal contacts with hearing pupils, both within and outwith school. Stewart and Ellis (2005) also pointed out that involvement in sport can provide avenues to success in terms of leadership roles.

However, communication issues can be problematic for deaf young people within the regular provision of extra-curricular activities. Noisy environments can restrict the effectiveness of personal amplification devices (such as hearing aids and cochlear implant speech processors) and, in some contact sports and swimming, devices need to be removed (Bat-Chava & Deignan, 2001; Stewart & Ellis, 2005). Information and instructions can be missed, particularly where activity leaders are unaware of how to amend their practice to facilitate inclusion – or are resistant to do so (Antia et al., 2002; Edinburgh and East of Scotland Deaf Society, 2002; Eriks-Brophy et al., 2007). Eriks-Brophy et al. (2007) described how, in one case, a Brownie leader refused to use a radio microphone to facilitate the inclusion of a deaf child who accessed information through audition. These authors also found that leaders could sometimes restrict the experience of deaf participants by having low expectations of their competence and ability to participate.

Lack of interpreting resources can hinder the participation of children and young people who are sign language users, both in terms of receiving information and making contributions to discussion (Antia et al., 2002; Edinburgh and East of Scotland Deaf Society, 2002; Stewart & Ellis, 2005).

Where any combination of these restrictions limit the sense of belonging, Antia et al. (2002) applied the construct of ‘visitorship’, as opposed to ‘membership’ to indicate the partial nature of social inclusion. Green (1990:306) described one boy’s painful experience of having to sit out on the bench during team sport because, in his words, ‘you can’t hear, that’s why’. They also referred to a parent’s description of their deaf son’s high achievement in the local Scouts group – but where he had ‘no real friends’ (op cit:302).

However, Eriks-Brophy et al. (2007), Schwartz (1990), Antia et al. (2002) and Stewart & Stinson (1992) have all highlighted the benefit of specially tailored inclusion programmes for leaders and hearing peers, sometimes facilitated by teachers of deaf children, and/or well resourced access resources, such as high quality interpreting facilities for sign language users or well-maintained and well-used radio aid systems for those who favour audition, which can all make a positive impact on deaf children’s experience. Cochlear implantation can make a difference to some children’s capacity to participate (Archbold et al., 2002), although, as already noted, this can be limited, particularly in sports environments. Antia et al. (2002) note that ‘deaf-friendly’ programmes have been found to be particularly important to the development of a sense of belonging among young people who were not strongly orientated to either spoken language or to American Sign Language.

As with the formation and maintenance of friendships generally, it is common for deaf children and young people to find positive benefit in attending structured activities with deaf peers. Where provision is designed for deaf young people, it can be assumed that ‘deaf-friendly’ communication strategies and attitudes are the norm, and serve to provide a comfortable cultural and linguistic environment where information is not missed. In the case of residential schools for deaf children, extra-curricular activities provide a means to occupy children while on site (Stewart & Stinson, 1992).

As noted above, fathers tend to play a lesser role than mothers in promoting the communication of their child. However, Eriks-Brophy et al. (2007) found that they sometimes gravitated to the role of activity leaders, particularly in sports, where they could better ensure that their child was included. Beazley & Moore (1995) also discovered that young deaf people themselves can develop their own inclusion strategies, such as, when having problems in following the instruction for a task in a swimming class, going to the back of the queue of hearing children in order to pick up the task by viewing other children demonstrating it. Although this could be described as resilience, Young, Green and Rogers (2008), in their review of relevant literature, have cautioned against a wholesale individualisation of the risks and disadvantages underpinning such resilience amongst deaf children, recommending attention to the social systems which contribute to them.

Ninety percent of young deaf respondents to a recent UK-wide survey by the National Deaf Children's Society (NDCS, 2008) reported that they wanted the organisation to provide opportunities for fun meetings with other deaf children and young people. The extent to which they favoured deaf-only activities was proportionate to their level of deafness and to the extent to which they used sign language. Stewart & Stinson (1992:134) noted that, in a study of 84 secondary age, mainstreamed pupils who attended extra-curricular activities, those who used sign language were more likely to attend deaf clubs. The authors suggest that deaf-only activities thus may act as a 'bridge' to membership of the Deaf community.

In fact, for many years, sport has provided an important focal point for social gathering and community cohesion within clubs and societies for deaf people generally (Lawson, 1991; Stewart & Ellis, 2005; Stewart & Stinson, 1992). The significance of this is emphasised by the fact that a series of UK-wide bodies have overseen and developed a wide range of all-deaf sports at regional, inter-regional, national and international levels since 1930 (Atherton, 2008). Stewart and Ellis (2005:62) noted the self-determination implications of the fact that such bodies are organised and run by deaf people. In terms of inter-club competition, Atherton (2008:289) commented that:

‘The sport itself was not necessarily the attraction, but it provided an opportunity for social contact with other deaf people and thus served as an important means by which the social cohesion of the deaf community was promoted and maintained.’

It has also been found that the overall psycho-social benefits of all-deaf sport tend to transcend individual language and communication differences, with evidence of linguistically diverse mainstreamed young deaf people and adults gravitating towards opportunities over time, as they become aware of them (Stewart & Ellis, 2005).

However, particularly in less well-populated areas, accessing activities for deaf children and young people can be challenging. The economic resources involved in fully supporting the involvement of any child, deaf or hearing, in extra-curricular activities, can be prohibitive for some families. This and the need for a sufficient level of shared values between parents and provider lead to some socio-economic skew to participation levels in out-of-school sports for all children (Kay, 2000). The added transport requirement for attendance at provision geared to deaf children and young people can be problematic (Antia et al., 2002; Stewart & Stinson, 1992). Transport can also be a problem for pupils who attend a mainstream school with a specialist unit or resourced base, and want to attend extra-curricular activities at their own school, whatever the hearing status of other peers involved (Stewart & Stinson, 1992).

Most studies on deaf children’s access to cultural education are focussed around formal school situations or structured extra-curricular activities such as sports clubs. Few studies have focused on the participation of deaf children and young people in visits and activities which could be deemed ‘cultural’ in terms of the society’s dominant perspective: for example trips to museums, galleries, cinemas, concerts etc. Eriks-Brophy et al. (2007) do make reference to the fact that some of the young deaf people in their study were particularly frustrated at the poor

quality of amplification facilities in cinemas – and tended consequently to avoid the experience.

Therefore participation in out-of-school activities can be seen to have special importance for deaf children, over and above the social and cultural potential relevant to all children. However, there have been shown to be barriers to involvement in opportunities which, for some children, can inhibit the potential benefits within both mainstream and all-deaf environments and can lead to marginalisation and isolation.

Before exploring what is known about the potential impact of such marginalising experience on mental health, the next section returns to the home environment to focus on the challenges parents face in providing opportunities for their deaf child to develop independence during adolescence.

Development of independence at home

The achievement of independence is a fundamental developmental task of adolescence, and home is a key location for the nurturing of autonomy at this stage (Zimmer-Gembeck & Collins, 2003). It is notoriously challenging for all parents to hit the right balance between providing the security of care and protection while increasingly taking the risks involved in encouraging children to become self-reliant, and there is evidence that parents of deaf children find it particularly hard to take such risks (Beazley & Moore, 1995; Eriks-Brophy et al., 2007; Gregory et al., 1995; Marschark, 2007). Reasons include concerns that their children will have problems in undertaking essential transactions because of communication barriers (for example, buying tickets for transport or asking for directions) and fears about their personal safety (for example, not being alerted by sound to impending danger such as traffic and perceived vulnerability to abuse by strangers). Parents of children with physical and learning difficulties are known to have similar problems in nurturing

independence because of fears about their child's relative vulnerability (Stalker, 2007).

Various authors have discovered specific evidence of parental restrictions to the types and levels of independence which would be normally be expected for children within the age ranges of their respective studies. Meadow (1980) cited evidence that deaf children are less often allowed out to play and Gregory et al. (1995) discovered that, even by an average age of twenty years, 42% of her sample were always accompanied by parents for at least some of their shopping. Eriks-Brophy (2007) and Beazley & Moore (1995) found parental limitations on deaf children's travel by public transport. However, although young people and parents in Gregory et al.'s 1995 study also indicated some concerns about public transport travel, the authors found contrasting evidence that many of those who attended special schools for deaf children had been allowed more independence than would be the norm over the years, due to long distance travel being essential – particularly in terms of their wide geographical spread of deaf friends.

Eriks-Brophy (2007:33) found that young deaf people can recognise the reasons for their parents' apparent over-protectiveness, but still be very frustrated by it. As one young deaf respondent put it:

‘Your parents, because they were with you all the time when you were young, very supportive and everything, it's harder for them to give you your independence... Sometimes you just want to say “Can you just get off my back!”’

It was noted earlier that hearing parents of deaf children tend to be more didactic in their play and early learning communication, which can militate against the development of key skills necessary for independent learning. Antia et al. (2002) found that this can extend to school situations, where parents and teachers collude, with good intentions, to create a ‘learned helplessness’. A propensity to dependence can also be created by parents trying to compensate for implications of their child's deafness by giving them preferential treatment or being disproportionately indulgent to them (Meadow, 1980). Again this tendency has similarities with the experiences

of parents of children with physical and learning difficulties, where a disabled child's behaviour can be 'seen through the lens of impairment' (Stalker, 2007:118). Meadow (1980) reported that some parents of deaf children try to balance out the conflicting pressures involved, by restricting the independence of their hearing children more than they would have otherwise done, in order to treat all their children more equally.

As with communication in the family experiences, also detailed earlier, there tend to be differences between hearing parents and deaf parents with regard to facilitating deaf children's independence. Meadow (1980) found that deaf parents were more likely to allow their children out to play independently and Marschark (2007) cited evidence to demonstrate that deaf children of deaf families tend to have more control over their own lives.

However understandable are the restrictions imposed on deaf children's self-reliance in family life, the results can have negative implications for deaf young people's social development. Green (1976) found that parental over-protectiveness can lead to an 'I am not able' attitude, and Meadow (1980) cites evidence that this can slow down the development of a deaf child's social maturity. Marschark (2007:209) detailed the constricting effect which over-dependence on parents can have on the establishment of a deaf child's internal 'locus of control' – essential for the development of emotional and social independence. He also described evidence that deaf children of deaf parents are less likely to be over-dependent on parents, are more likely to establish their internal locus at age-appropriate times, and thus tend to be better adjusted, socially and emotionally.

Although authors are generally careful to point out that there is variation in the extent to which deaf children and young people experience problems as a result of parental over-protectiveness, it is likely that there may be some impact on the mental health of those whose emotional and social development is affected – particularly where they also experience isolation and loneliness in the kinds of situations described earlier in the chapter.

Mental Health Issues

It is not uncommon, as has already been shown, for deaf children to miss out on information and quality social contact in their relationships with hearing family and friends, in the context of some parents conceptualising deafness in negative terms; all of which can lead to feelings of isolation and of 'not belonging'. Antia et al. (2002) described membership of a community as a basic human need; and concerns have regularly been raised, in research literature, about the potentially damaging effects of deaf young people not being able to fully identify with a 'phonocentric' hearing community (Corker, 1998; Deaf Ex-Mainstreamers' Group, 2003). At the same time, Corker (1998) contends that those who most vehemently argue for the separateness of Deaf culture, with sign language at its core, have themselves created a hegemony of 'Deafhood' among deaf people which can be excluding and disempowering for deaf people who do not use sign language. Thus, while it is increasingly recognised that identification with more than one community is possible, and can be advantageous (Marschark, 2007), there are particular anxieties about those who are in an identity limbo; that is, not fully identifying with either 'hearingness' or the Deaf community (Deaf Ex-Mainstreamers' Group, 2003; Kyle, 1991:45).

Although almost two thirds of young deaf people in Gregory et al.'s (1995) sample reported that they were happy, many said that they were lonely and had feelings of not belonging. The authors had serious concerns over the self-esteem of seven of the sample, who had very negative feelings about their deafness: one indicating that he felt it was better to be dead than deaf. The most significant factor was felt to be lack of parental acceptance of deafness, exemplified by: use of the term 'normal' to describe hearing peers; not allowing their deaf child to watch programmes for deaf viewers; discouraging them from attending the local Deaf Club and indicating general disappointment in having a deaf child (Gregory et al., 1995).

In terms of family communication, there is evidence that poor communication between parent and deaf child can restrict the child's socio-

emotional development and their sense of being part of the world. Parents in Meadow's (1980) study expressed frustration at deaf children's perceived lack of ability to understand the feelings of others. However, she found that the deaf children were less likely than hearing children to have emotions explained and discussed. More recently, Woolfe and Smith's (2001) study demonstrated that young deaf children of hearing parents were likely to have more than average difficulty in understanding that other people have varying feelings and individual responses to events. Vaccari and Marschark's (1997) literature review emphasised the link between impoverished parent/deaf child communication and the likelihood of the child having limited understanding of the relationships between events, behaviours and emotions - and of the increased likelihood of impulsivity. All of these issues can lead to misunderstandings and to social and emotional difficulties.

Bearing these situations in mind, it is perhaps not surprising that there is some evidence of higher than average incidence of mental health problems among deaf young people (Hindley, Hill, McGuigan, & Kitson, 1994; Wallis, Musselman, & Mackay, 2004) – a situation which mirrors that of children and young people with physical and learning disabilities (Meltzer, Gatward, Goodman, & Ford, 2000; Stalker, 2007).

However, the production of relevant statistical information is not straightforward and data needs to be treated with some caution. Vostanis (2007) describes the complexities involved in collecting information about mental health in the adolescent population generally, including: a lack of definitional clarity among professionals and services; the fact that young people develop at different rates; the stigma attached to mental health disorders, which may skew self-reporting results, and difficulty in defining the level at which particular behaviours, which relate to ordinary adolescent changes, become 'strange' (for example, withdrawn behaviour, unhappiness etc).

There are added problems in collecting data within the deaf population. Marschark (2007) pointed out that older statistical information is particularly

unsatisfactory, as it was not uncommon, in the past, for deafness to be misdiagnosed as a learning or psychological difficulty. Even with more recent research, major problems are the paucity of appropriate and reliable assessment tools to use with deaf children and young people, most assessments being normed on hearing populations (Hindley et al., 1994; Wallis et al., 2004), and the rarity of appropriate language and communication skills among those administering tests (Marschark, 2007).

The end result is a relatively small number of studies which use diverse methods and types of samples, and which show a wide variety in results reported. However, Wallis et al. (2004:2) stated that, bearing all the above in mind,

‘the bulk of the literature suggests that, in general, deaf children and adolescents are at greater risk for psychosocial maladjustment than their hearing peers’

While complexities and research limitations restrict the degree to which any causal connections can be made, deaf children of deaf parents consistently fare better in terms of a lower incidence of psycho-social problems (Polat, 2003; Wallis et al., 2004), although it is feasible that, as with educational achievement, key factors are: shared, high quality family communication; acceptance of deafness, and more encouragement of independence - as have already been highlighted - rather than parental hearing status, per se. Indeed, both Marschark (2007) and Wallis (2004) highlighted the strong connection between early, shared language and communication in the family and reduced incidence of mental health problems among deaf teenagers, and Leigh, Robins, Welkowitz and Bond (1989) found a connection between maternal over-protection and levels of mild depression in deaf college students.

Educational placement has also been found to be a significant factor, with deaf children in mainstream schools more often demonstrating higher levels of mental health problems relating to isolation (Marschark, 2007). The connection between this and friendship patterns is likely to be strong, given the importance of peer networks to the school experience – and the fact that there has been shown to be a correlation

between friendship networks and the level of mental disorder of children and adolescents generally (Meltzer et al., 2000).

Therefore, bearing in mind the caution needed over causality, it seems as though specific situational factors may impact on the mental health of deaf children to some extent, as may have been predicted from previous subsections on family communication, friendships, inclusion in activities and development of independence in adolescence.

Having explored the impact of family relationships, friendships, and extracurricular activities on the educational and psycho-social development of deaf children and young people, I will now return to the concept of symbolic capital and use it as a lens through which to view some of the key issues so far raised.

The application of a symbolic capital framework

Bourdieu's focus on the role of language was primarily in terms of the way that linguistic differences between families of different social classes impact unequally on children's chances to distinguish themselves educationally (Bourdieu & Passeron, 1977). Evidence has been given that the 'linguistic capital' of deaf pupils is being restricted by something over and above the effect of class, and that the nature of parental communication is likely to be a key factor – particularly in the critical, early years of language development.

This seems to tie in with Coleman's emphasis on the fact that it is the **quality** of communication between all parents and their children, rather than just the physical presence of adults in the family, which makes the most impact on the child's development.

'If the human capital possessed by parents is not complemented by social capital embodied in family relations, it is irrelevant to the child's educational growth that the parent has a great deal or small amount of human capital.'
(Coleman, 1988:89)

The fact that the vast majority of deaf children are born into hearing families means that most deaf children are in situations where they do not have full access to the language around them and where a parent's 'primary pedagogical work' can be beset by challenges in facilitating their child's language development and in conceptualising deafness positively.

Assuming a deaf child's habitus is their internalised synthesis of external and internal influences and aptitudes, and that language is an 'appropriating capacity' within the habitus, then external influences should, as far as possible, unlock and develop innate language potential, in order to build capacity for the appropriation of knowledge and skills. This seems to tie in with Rodd and Young's (2009) call for deaf education services to take a holistic view of deaf children's assessment and of case prioritisation – taking the diversity of abilities and circumstances into account. Knoors' (2007) call for a 'no exclusion' spectrum of specialist linguistic advice and service provision to families, inclusive of sign language, also seems applicable to this construct, given that it has been shown that there is such diversity among the population of deaf children, and that using sign language early can be advantageous to development. However, I have described evidence of a lack of resources and of a prevailing discourse of deficiency, in relation to both deafness and sign language, with the result that professional advice and service provision can be biased, restrictive and geographically variable.

In this context, evidence of restrictions to the deaf child's acquisition of language at home and to participation in a hearing family's communication generally, can be viewed as directly impacting on the 'appropriating capacity' of language, within their habitus, and thus central to the accumulation of cultural capital, including the 'institutionalised state' of educational qualifications. Where there are difficulties in accessing/participating in out-of-school cultural activities, this can also be construed as limiting the building of cultural, as well as social, capital.

In Bourdieu's terms, the 'unceasing effort of sociability' is a major driving force in the building of social capital (Bourdieu, 1986:250). He, James Coleman and

Robert Putnam have been credited as being the seminal contributors behind the development of the concept (Schuller et al., 2000). Catts and Ozga draw particularly on Putnam's work by dividing social capital into three forms: 'bonding', 'bridging' and 'linking' capital (Catts & Ozga, 2005). The constructs of 'bonding' and 'bridging' arguably have particular relevance to this thesis.

The importance of 'bonding' is the value inherent in a sense of shared identity and security. Evidence in this chapter provides reason to speculate that the more that a deaf child is linguistically excluded from family communication, and the more that deafness is negatively conceptualised by parents as 'deficient' rather than 'different', the more that there is likely to be weakness in bonding capital, and therefore a negative impact on the emotional security provided by shared identity.

Although this study focuses on family rather than school life, the discussion of literature relating to peer relations has necessarily included reference to school placement, because there is such an overlap between friendship networks formed and maintained at home and in school. Antia et al.'s (2002) notion of 'visitorship' is borrowed, in later chapters, to describe the partial nature of some deaf pupils' inclusion in mainstream education. The term indicates limited bonding in friendship networks with hearing pupils, which can impact on the accumulation of bonding capital, as well as on incidental knowledge and information - thus implying limitation to cultural as well as social capital. Evidence of profound feelings, among some young deaf people, of 'not belonging' in hearing networks has been explicated in this chapter.

While it has been demonstrated that some children experience restriction to bonding capital by a sense of 'visitorship' in their participation in structured activities outside of school, it has also been shown that some activities can enhance bonding social capital and cultural capital through motivation engendered by shared interest and by experience of success. It has been suggested that this can be particularly relevant to sporting activities. Participation in sport can be construed as facilitating the accumulation of elements of 'embodied cultural capital', or 'physical capital' -

impacting on the positive presentation of self and self-identity – as well social capital, through access to social contacts (Shilling, 2003; Warde, 2006). Collins, (2003:69) has suggested that social capital is actually an essential requirement for taking part in sport:

‘[it requires] groups of supportive friends and companions,
including some who share the same desires to take part’

While the distinctions between complex permutations of social class, individual sports and conversion of physical capital into material resources are not addressed here, it could be argued that the general symbolic conceptualisation has particular significance for deaf children, given the evidence that sport can be an important means of achieving credibility and belonging within both deaf and hearing networks. Warde argues that capital can be built, to a limited extent, by spectating sports, as well as by participating in them. Where parents facilitate participation in activities and help their child to form and maintain friendships generally, they can be seen to provide ‘bridging’ capital. Examples of parents becoming activity leaders in order to help to facilitate the inclusion of their deaf child have been highlighted in this respect.

Catts (2008) has conceptualised parental bonding capital as two ends of a continuum: at one end a ‘safe and secure platform to support the child as they develop their own linking and bridging social capital’, and at the other, a ‘fenced paddock to which the parent holds the gate key’. In terms of parental facilitation of the self-reliance of their deaf child, it seems evident that, in balancing these two forces, hearing parents are likely to be pulled towards the gatekeeping role, out of concern for their child’s perceived vulnerability, and/or a perceived need to fulfil a more didactic role in language teaching.

In some cases, it has been shown that this gatekeeping role can extend to creating a barrier to their child’s formation of close networks with deaf peers. Where hearing parents have actively fostered their child’s friendships with other

deaf children, this can be seen to be facilitating their child's bridging into an alternative community network, assuming the definition of bridging capital provided by Catts and Ozga (2005:2):

‘a resource that helps people to build relationships with a wider, more varied set of people than those in the immediate family or school environment.’

There are contested issues around the definition of community, in relation to deaf people (i.e. including those who do not use sign language), but there are strong arguments that there is an alternative linguistic and cultural bonding network, or community, where shared behaviours are predicated on a positive conceptualisation of deafness (Lane, Hoffmeister, & Bahan, 1996; Padden & Humphries, 1988). The notion of there being an alternative ‘deaf identity’, or ‘different centre’ – or, in terms of symbolic capital, a collective deaf habitus (Thoutenhoofd, 2005) - experienced by populations of deaf people, has profound implications for a child's individual habitus and for their accumulation of both social and cultural capital. Positive versus negative conceptualisations of deafness correlate with opposing views evidenced among parents on the benefits versus disadvantages of membership of deaf community networks, ranging from discouragement to attend a Deaf Club to assisting their children to travel long distances to see deaf friends. It seems that an ‘either/or’ perspective can exist, with a fear, in some cases, that membership of a ghetto-like world could impact negatively on future social status and earning capacity (economic capital) within a society dominated by hearing culture.

However, evidence that deaf children of deaf parents tend to fare better educationally and psycho-socially suggests an alternative scenario. How far shared identity plays a part can be conjectured, but, as has been shown, evidence does not point to the deafness of parents, per se, being the cause of generally superior levels of social and cultural capital among their deaf children, but rather the fact that they, along with some hearing parents, tend to normalise deafness, provide a high quality, inclusive linguistic environment and be less didactic in communication. As Marschark (2007:101) noted:

‘Most deaf children will grow up to be just as emotionally well-adjusted as hearing children, but they need the same kind of parenting and the same kinds of experiences as their hearing peers.’

The fact remains that, in terms of problematic outcomes among deaf children and young people generally, as a whole population, they tend to underachieve educationally, and some experience social and emotional problems, which can be as extreme as to cause mental health problems.

Few studies focusing on the experience of deaf children and young people have made reference to the theoretical concept of symbolic capital, but two recent articles have applied it explicitly to deaf pupils’ school lives. In her in-depth case study of a cochlear-implanted primary school child in a mainstream situation in New Zealand, Mc Kee (2008) argued that, while the country’s educational policy at macro level constructs deaf children as bilingual learners, thus implying legitimisation of sign language and Deaf experience as valid alternative sources of cultural capital, the reality of practice at school-level belies this. Wilkens and Hehir’s (2008) discursive article concurs with the arguments I have used here to endorse the worth of a social capital framework as a lens through which to explore the value of both deaf and hearing relational networks, arguing the need for bilingual-bicultural social capital value to be factored into policy and practice developments.

The benefit of using symbolic capital as a lens enables the huge diversity of internal and external influences to be taken into account – recognising the uniqueness of each child’s synthesis of infinite permutations of internal and external characteristics and influences, from individual attributes to structural societal influences.

Chapter two: Methodology

In this chapter I will begin by setting out the research questions which lead from the literature reviewed in the previous chapter. As these questions will be addressed by data which was gathered within a subsidiary project of the Achievements of Deaf Pupils in Scotland (ADPS) project, I will then provide a brief description of salient points about this parent project and of the development of the subsidiary project concerned: the Family Survey. In particular I focus on the collaborative relationship with parents in the development and execution of the Family Survey, setting this in the context of a prevailing discourse, within policy and legislation, of 'parents as partners'. The process of designing the research instrument used in the Family Survey is described, including a description of key aspects of content. An account is then given of efforts made to meet challenges experienced in the collaborative process of developing, distributing and maximising the return rate of the survey instrument: a postal questionnaire. There follows an exploration of factors likely to have influenced the final response rate. Finally, key methodological issues are raised about the way the data specific to this thesis was analysed, and implications for the validity of these data, before a description of the analysis process itself.

Research Questions

As described in the introduction to this thesis, my professional experience in work with deaf people spans both educational and social work contexts. As well as engendering an interest in collaborative work with parents, and consolidating a belief in the epistemological import of their perspectives, the experience also gave me a particular interest in specific challenges faced by deaf children and their families outside of the formal educational environment, and laid the foundations of a standpoint which will be explicated later in this chapter. The particular choice of focus for the research questions, on which the thesis is based, at least in part reflects

this interest. As will be further explored within this chapter, the development of these specific research questions, and the application of a symbolic capital theoretical framework, were undertaken on a post hoc basis and therefore did not affect the design of the data collection instrument, per se.

Three questions are posed, all of which are addressed by the analysis of parent reports:

1. What is the quality of communication between deaf children and family members?
2. What are the extent and nature of deaf children's participation in social life and structured activities outside school, and of the degree to which deafness-related issues impact on their participation?
3. How far do deafness-related issues affect parents' expectations for their deaf adolescent children to be independent outside of school?

It should be noted that, in constructing and answering the research questions, it has been assumed that deafness may interact with factors leading to a higher likelihood of disadvantage, rather than intrinsically being the cause of disadvantage, per se (Young et al., 2008).

I intend to address the questions by exploring relevant sections of data collected during my employment within the Achievements of Deaf Pupils in Scotland (ADPS) project. I was engaged as the only full-time Research Associate, among a team which also included: a part-time Project Director; a freelance database developer and a full-time administrator. As such I was involved in all aspects of the research, but specific responsibilities included: collaboration with 'stakeholders', survey design and maximisation of survey response. I periodically adopted more overall responsibility, particularly in the relation to the Family Survey. In this respect, the influence of my professional background and standpoint could be seen to have had some influence on the research design.

The ADPS project

As was indicated in the previous chapter, deaf children, historically and persistently, have under-achieved educationally compared to hearing children. A landmark large-scale study in the late 1970s provided more detail about this attainment gap in the UK than had previously existed (Conrad, 1979). However, twenty years later, an extensive literature review, commissioned by the UK government, found that, in the intervening years, there had been a disappointingly low production of robust, empirical evidence, to move the situation forward significantly (Powers et al., 1998). The review particularly lamented the shortage of large scale, longitudinal studies, and the Achievements of Deaf Pupils in Scotland project was established in November 2000, and funded by the Scottish Government (then known as the Scottish Executive), to address this need within Scotland. The funding was channelled through the Scottish Sensory Centre (SSC), which is based within the Moray House School of Education at the University of Edinburgh. The SSC's advisory group, comprising representatives of 'stakeholder' groups, also took on the role of official advisory group for ADPS project.

The main focus of the ADPS project was an annual national survey of all deaf preschool and school children and young people, funding for which ceased after five consecutive years of collection. Data on achievements, and factors which may affect achievements, were gathered from teachers of deaf children, who sometimes found it expedient to delegate completion of relevant sections of the survey instrument to other professionals, such as educational audiologists and speech and language therapists. Paper questionnaires were employed as research instruments.

The target population was defined by level of service provided by educational services, rather than by the hearing loss level of individual children and young people, in recognition of evidence that mild hearing loss can sometimes impact on learning (Goldberg & Richburg, 2004; Most, 2004). This population was known as ADPS 'Group A' and included all preschool children diagnosed as deaf and known to education services, as well as school pupils in the following categories: those who

attended a school for deaf children; those who attended a mainstream or special school with a special unit for deaf pupils and those who attended mainstream provision and received two or more visits per year from a teacher of deaf children. The age range thus stretched from recently-diagnosed babies through to school-leavers. Services were asked to complete an annual return for each preschool child or pupil within these categories. In addition, after 2003, data on examination results was provided directly to ADPS by the Scottish Qualifications Authority (SQA), for those 'Group A' pupils whose unique SQA code had been supplied by teachers. Pupils who received only one visit a year, by a teacher of deaf children, or whose names were held on 'monitoring lists', were known as 'Group B' pupils. Basic characteristics of this group (numbers, hearing loss level, gender) were collected only on an aggregate basis, and only for the first two years of the project. As will be apparent later, this way of categorising had implications for analysis of data used in this thesis.

The database allows for individual and group level data to be tracked longitudinally over the 5-year span of the project. By 2005 there were records for 2,122 'Group A' deaf children and young people.

In addition to the pupil survey, the project team also undertook a number of 'snap-shot' surveys with, respectively: teachers of deaf children; heads of deaf education services, and parents (the ADPS Family Survey), all of which underwent a process of ethical approval through the University of Edinburgh's Ethics Approval Procedure. The Family Survey is the source of data for this thesis.

Collaboration with 'stakeholders'

A basic tenet of the project was to collaborate with a wide range of 'stakeholder' interest groups and individuals in the design and content of the research, with the aim of ensuring that both the process and outcomes would be optimally responsive and meaningful. Thus, in addition to the official advisory group, the project also developed networks of individuals and groups representing particular interests. This was, in part, motivated by the desire to further the

possibilities of knowledge transfer from research to policy and to professional practice (Ozga, 2004). However, the inclusion of parents, and of deaf people themselves, as stakeholders, was also in recognition of an imbalance of power in the construction of the prevailing epistemology in deaf education, and thus acknowledgement of a need for ‘Research that respects the participation of the people it seeks to understand...’ (Sheridan, 2002:224), grounded, at least to some extent, in ‘experiential knowing’ (Heron & Reason, 2001:183).

In terms of involvement of parents, the project developed a ‘parent perspectives’ group, which was, arguably, in tune with a well-established, if contested, drift, in educational policy and legislation generally, towards the acceptance of the value of participation and support of parents in the process of planning and delivering educational programmes to their children – a discourse of ‘parents as partners’.

Parents as partners

Although there has been considerable debate over the past thirty years about the character and limitations of potential partnership between schools and parents (Gillespie, 2008; Munn, 1993), and concerns expressed, throughout this time, about the implications of underlying authoritarian governmental assumptions (Kasama & Tett, 2001), over recent years, legislation in Scotland has consolidated the legal rights of parents to be involved in their children’s education, and in school education generally (The Standards in Scotland’s Schools etc. Act, 2000; The Scottish Schools [Parental Involvement] Act, 2006). One of the main driving forces behind this move was the recognition of the link between parental involvement and pupil achievement (Gillespie, 2008), a link already noted in the previous chapter.

From the time of the Warnock Report (Department for Education and Science, 1978) and the Education (Scotland) Act, 1980, the discourse of ‘parents as partners’ has also prevailed within the policy and legislation frameworks associated with ‘special educational needs’ (SEN) and, more recently, ‘additional support for learning’ (ASL) (O’Connor, 2008; Riddell, 2002; Scottish Executive, 2005; Scottish

Office, 1998; UNESCO, 1994). The frameworks promote parental involvement in decision-making about specific assessment, placement and access/support arrangements, in addition to more general planning and curriculum issues. There have, however, been ongoing tensions over the extent to which potential for power-sharing within the policy parameters has been compromised during the process of implementation (O'Connor, 2008; Riddell, 2002).

Although a distinct, culturally and linguistically-based construct has been suggested as more appropriate (Brennan, 1999), deaf children and their families have always been included in these SEN and ASL frameworks, and thus similar tensions exist as for all included parents. In particular, as noted in the previous chapter, few hearing parents have had prior experience of deafness and are therefore the vast majority of parents are especially reliant on professionals for information and advice on linguistic, cognitive and cultural implications of their child's development and education. As also highlighted previously, there are enduring concerns about the negative effects where the resultant imbalance of power is manifested in the restriction of information, or in the provision of biased and misleading advice, to parents (Young et al., 2006).

Therefore, in this context, the intention to involve parents as key 'stakeholders' in the ADPS project and, particularly, as partners in the Family Survey, indicated both an epistemological concern to acknowledge the value of parental experiential knowledge and perspective, and also a specific intention to facilitate empowerment, through shared control of process and outcome of the research. First, the extent and nature of the collaboration will be detailed within a general account of the development of the Family Survey.

The Family Survey

The rationale for the Family Survey was partly born of the awareness, among the ADPS research team, of issues raised in the previous chapter, particularly the evidence of links between family life and the achievement and social development of deaf pupils. However, a strong steer also came from parent groups and individuals, who were already involved in the ADPS ‘parent perspectives’ network. The National Deaf Children’s Society (NDCS) was the main parent organisation represented, through the involvement of key staff from the national Scottish office, and of delegates from affiliated local Deaf Children’s Society (DCS) groups throughout Scotland. Eliciting information about deaf children directly from families was suggested for two main reasons. The first reason was to lessen the burden on teachers; as a representative of one of the affiliated DCS groups said, in a seminar presentation about ADPS in 2003:

‘We realise that this is going to be a difficult job for teachers to do, but we, as parents, would be only too happy to help – please use us to get the information.’

Secondly, NDCS and DCS groups provide services to families of deaf children. Representatives felt that the greater understanding provided by a direct survey of families would assist in the planning of support services and the development of initiatives with families. The ultimate aim, in both cases, was an improvement in the quality of life for deaf children in Scotland and their families.

A working group was formed, comprising the ADPS research team, representatives of NDCS and local DCS groups, and individual parents who had expressed interest through the ADPS ‘parent perspectives’ network. The fact that the ADPS annual pupil survey had already established data records on individual pupils provided initial direction for the nature of the Family Survey, in so far as it was assumed that it would be possible to enhance and complement the statistical data in the pupil database with the new data collected from families. It was also taken for granted that the target group would be the total population of parents, rather than a

sample group, in line with the fact that the main ADPS database was already covering the national population of deaf children and young people.

Arguably, the working group fulfilled the role which can be performed by focus groups in grounding initial research design in experiential reality (see, for example, Fowler ([2002])). However, as will be described, it could also be argued that parents here had a higher level of involvement than this – as co-designers rather than as members of a reference focus group.

The rationale for application of symbolic capital as a theoretical framework was explicated in the previous chapter. However, as noted earlier, the framework was applied *after* the Family Survey research instrument was designed and the data processed. Therefore the next section describing this design process should be viewed in this context; the implication for data analysis will be explored later in the chapter.

Design and Content of the Research Instrument

It should be noted that the research team shared a standpoint which: embraced cultural and linguistic elements, as well as ‘deficit-based’ elements, in its conceptualisation of deafness; considered that the linguistic spectrum offered to deaf children and their families should not exclude BSL; and viewed D/deaf networks in positive terms – as alternative networks for deaf people of all ages. Therefore the design of the Family Survey, as with the pupil survey, reflected this broad standpoint. For example, BSL was always referred to as a language rather than a mode of communication and it was taken for granted that questions about friendships with deaf children would be presented in an identical way to questions relating to friendships with hearing children.

Rationale for a postal questionnaire

The fact that questionnaires were used for the pupil survey established an expectation that the same method would be used for the Family Survey. As we wished to include the whole population of parents, the main advantage, for us, was that the use of questionnaires made it administratively, and financially, feasible to elicit data from well over a thousand people, scattered throughout such a wide geographical area. Other advantages, which are among those listed by Gillham (2000), Bernard (2000), Burns (2000) and Fowler (2002), include: minimisation of risk of interviewer bias; the sense of security provided by anonymity; completion time being at the respondent's convenience; analysis of data being comparatively straightforward and, finally, the likelihood that the results would provide robust indicators for future, more in-depth study. However, all four authors also outline disadvantages, including: lack of control over how accurately/reflectively questions are answered, and how they are interpreted by respondents; the relative superficiality of data outcomes, due to the need for brevity; lack of motivating personal contact, and access barriers for those whose literacy levels are low.

Bearing these pros and cons in mind, it was decided that a postal questionnaire would be used, with concerted efforts made to minimise problems. An electronic version was ruled out, in recognition of the fact that not all parents would have access to the internet at home.

Concerns about superficiality and lack of control over question completion were addressed, to some extent, by a decision to include open, as well as closed, questions throughout the questionnaire. This will be further explained in the following sub-section. Issues relating to the lack of personal contact and to literacy will be addressed at relevant points throughout this chapter.

Closed and open questions

Deciding to include both open and closed questions was in tune with my own research standpoint, which is arguably within the realms of critical realism (Sayer, 1984): basically interpretive, because of the value placed on individual constructions

of reality, while, at the same time, pragmatic, through an acceptance that there are some elements of reality which are independent and factual enough to be worthwhile measuring. Thus I could value the statistical data produced by closed questions, while wishing to provide as much space as possible for open questions, and while accepting that the knowledge produced would inevitably be contextually constructed, and partial in nature.

Topics for construction of closed questions were drawn from a combination of knowledge of previous research and experiential knowledge among the Working Group members, as will be further explained below.

It was intended that the open questions would enable respondents to explicate further their responses to closed questions, thus aiding clarification of intention, and would also provide richer detail in the data – a ‘greater level of discovery’ (Gillham, 2000:5). Also, it was expected that they would provide the opportunity for identification of issues which may indicate the need for further study. In terms of the focus of this thesis, the richest level of such qualitative detail was required in relation to the impact of their child’s deafness on participation in activities and social life. Therefore it was decided to follow each closed question about participation with an open sub-question about impact of deafness. It was felt that this offered the optimum compromise between easily-analysable data and richness of response.

A further usage of open questions was when eliciting descriptions of both ethnic background and of any physical and learning difficulties. The purpose was to provide a more nuanced categorisation than that possible through limited closed selections.

The main drawback to open-ended questions is that they may be vague, ambiguous and/or incomplete, and are less straightforward to analyse (Burns, 2000; Cohen, Manion, & Morrison, 2000; Fowler, 2002; Gillham, 2000), so this was taken into account, as far as possible, when drafting the questionnaire for piloting and for planning the data analysis.

Development of questionnaire content

In order to establish questionnaire content, members of the Working Group pooled suggestions for topics which would best fit with the purpose of the research, as detailed above, following the well-established research practice of developing specificities of survey focus from initial primary objectives (Cohen et al., 2000; Robson, 1993). Subsidiary topics were identified, some of which directly related to the pupil database (for example: socio-economic information; onset and aetiology of deafness; physical and learning difficulties; language and communication in the home etc) and some were proposed by parent group members (for example: views on parental support, knowledge of NDCS; 'placing requests' for school placements; patterns of communication among specific family dyads, such as deaf child/grandparent etc).

Thus the content was developed from both academic and experiential knowledge, with outcomes intended to inform research, policy, and professional communities, as well as parents and deaf young people themselves. As already noted, parents could be seen as having been co-designers of the instrument, in line with the intention to share control of the process, rather than having had a more marginal role as members of a reference group.

Topic areas specifically relating to the focus of this thesis (family communication generally; participation in out-of-school and family activities) were generated by both ADPS staff and parents, without their development being the particular province of either group.

Once a list of subsidiary topics were identified, I took responsibility for itemising specific areas of required information within each topic, each of which led directly into the formation of a question. This again follows established survey procedure (Cohen et al., 2000; Robson, 1993).

Representatives from the Minority Ethnic Learning Disability Initiative (MELDI) and the Centre for Education in Racial Equality in Scotland (CERES) were co-opted onto the group, to ensure that questions relating to ethnicity were included and expressed in the most appropriate way. At the time CERES was addressing concerns, nationally, that most surveys tended to provide an overly-restrictive categorisation of ethnicity. They advised a then-pioneering strategy of inviting respondents to use terms with which they felt most comfortable, in an open question, and providing examples of possible terms for clarification. It was accepted that this would mean additional work in manually coding responses, but would provide a more meaningful description of constructs of ethnic background. Questions on faith and on participation in religious worship were also included, after discussions with MELDI on the relationship between religion and culture.

Where possible, questions were harmonised with other major relevant surveys, in order to allow for comparative analysis. In particular, key socio-economic questions on parental employment, highest qualifications and income were harmonised with those in the Scottish School Leaver Survey (SSLS). A consultant from the Scottish Household Survey also advised on the format of socio-economic questions.

As recommended by Gillham (2000), Bernard (2000) and Burns (2000), care was taken to assist respondents by, as far as possible: creating an attractive and well-spaced appearance (including use of colour); ordering and clustering topics logically; keeping questions short and unambiguous, using 'tick box' selected responses where feasible; avoiding leading questions as well as those which are confusingly 'double-barrelled'; using a minimum amount of 'routing' to later questions; and providing minimal, clear instructions throughout. Cohen et al. (2000) note that targeted incentives can aid completion rate. It was decided by the Working Group that a prize draw would be used: respondents were invited to return a draw entry by a deadline date with their completed questionnaire. The prizes were two tokens for spending in a high street store, to the value of £25 each.

Scales were used for some questions where opinions or estimations were required from respondents, in order to elicit responses which could be easily analysed. For example, parents were asked to rate the frequency of participation of their deaf child in specific activities on a three-category scale, with '1' representing 'frequently' and '3' representing 'never'. In another example, parents' ratings of the quality of communication between their deaf child and family members were elicited via a 5-category scale, with '1' representing 'communicated very well' '5' representing 'not well at all'. In both examples, the middle values of the scales were simply numerical (respectively, '3' and '3', '4', '5' for these two examples). The intention was that this would optimise neutrality. However, this posed a dilemma when reporting findings, as it meant inevitably imposing a meaning on the interim values which may or may not accurately reflect the intention of individual respondents. Even when all categories are more clearly labelled, Fowler (2002) warns that categories used as tick-box options are constructed, rather than being absolute measurements, and that therefore this needs to be made clear by reporting results in the context of comparative, rather than general, statements.

Furthermore, caution has been advised in using scales generally. Gillham (2000) points out that they are limited in usefulness without further information; this was addressed, at least in part, by the use of follow-up, open-ended questions.

The collaborative nature of the instrument design meant that different perspectives had to be accommodated. Sometimes this led to challenges which needed to be addressed.

Challenges within the process of collaboration

A particular challenge arose when experiential and academic standpoints conflicted. I, and other members of the ADPS team, were keen to include survey questions which would elicit detailed socio-economic information from respondents. This was due to evidence that socio-economic factors have been shown to be significant in all pupil attainment, including that of deaf pupils, as noted in the previous chapter. However, some parent members of the group balked at the

implication that indications of deprivation, in terms of location of residence, income and educational levels, suggest poor parenting. This was felt to be potentially offensive – particularly by one member of the group, whose postcode fell within an area where the population are known to experience significant privation. After some debate, a compromise was eventually reached: it was agreed that socio-economic questions would be included within a pilot study and that feedback would be particularly sought on this issue.

Contrasting views, among both the research team and parents, were also expressed about the inclusion of questions which asked parents to indicate the nature and extent of their child's participation in cultural activities. Concerns were expressed that the inclusion of such questions could create normative assumptions and pressures, and risk engendering feelings of guilt, if lack of participation was perceived by parents as an indication of inadequacy. In Bourdieu's terms, this arguably implied an act of 'symbolic violence' by appearing to valorise a 'cultural arbitrary' (Moore, 2004). Again, a compromise was reached; in this case that care would be taken to frame the questions in such a way as to reduce the risk as far as possible.

A further challenge lay in balancing the desire to include all the suggested topics for questions with the need to restrict the questionnaire to a length which would optimise the number of responses. The process of prioritising items highlighted the fact that the research team ultimately were the most powerful partners in the collaboration. This was partly in terms of simply having more time and resources to devote to the complexities of the survey design, but also, arguably, may have also been in terms of the authority inherent in the project team's University status. Thus the research team tended to take the lead in the management of the process and in making final decisions about priorities. Nevertheless, apart from the differing views over socio-economic information, there was general consensus about which items to lose in order to limit size. Examples of topics/items relinquished included: type of housing accommodation; personality traits of child and dominant hand of child.

The collective nature of the design process was only one of a number of factors leading to trade-offs during the design process.

Other trade-off situations

Firstly, there is a general recognition that a questionnaire format can be off-putting for those who have low level literacy skills, as already mentioned above, and as highlighted by Bernard (2000) and Fowler (2002). As this group is likely to be disproportionately located among those with low socio-economic indicator levels, the use of written questionnaires could potentially lead to a socio-economically skewed response. Efforts were made to ensure that the language in the text was as clear and unambiguous as possible and a network of parent volunteers provided a back-up service to assist with completion, as will be described below. Despite this accommodation, it was accepted that there would still be a risk of missing out on ‘hard-to-reach’ parents, resulting in some degree of socio-economic bias in response.

However, it was possible to specifically address situations where the first language of respondents was not English. Although the cost of fully translating the questionnaire into all the 138 languages spoken in Scotland (Scottish Government, 2008) would have been prohibitive, a compromise plan was worked out, in consultation with both spoken language and British Sign Language (BSL) interpreting agencies. Arrangements are detailed in the ‘distribution’ sub-section below.

Secondly, trying to achieve a balance between level of detail and brevity of instrument sometimes resulted in missing out important nuances. For example, data on language does not comprehensively include the extent of usage of manual modes of English, and thus is limited in the extent to which it reflects the complex reality of the usage of sign vocabulary in deaf children’s linguistic situations. Also, due to slight differences in question presentation (and the lack of objective measures), the distinctions between the BSL as main language and its use bilingually with English

were relatively arbitrary when comparing Family Survey and ADPS populations. In most cases the two categories have been combined for the purposes of analysis.

Attempts to resolve the detail/brevity balance dilemma also caused analysis problems where only one open question was provided at the end of a list of closed, tick-box options, rather than one open question per tick-box. For example, in the case of a specific question about independence, it was not always clear which type of independence activity the comment related to, thus limiting the richness of data in relation to specific indicators.

It is argued throughout this thesis that there is value in the inductive approach taken to the elicitation of qualitative data from open comments made by respondents. The trade-off, however, is the fact that more use of more specific, closed-option triggers can reduce the potential for ambiguity and overlap in responses.

The importance of a pre-test or pilot exercise is well documented, to test out how well the survey instrument works in realistic conditions: for example, to identify any ambiguities in questions (Burns, 2000; Fowler, 2002; Gillham, 2000). It was decided that the most efficient means of piloting the questionnaire would be to invite parents of deaf children to attend a day's event, enabling feedback to be discussed in a group, as well as to be fed back individually.

Piloting the research instrument

Members of the Family Survey Working Group offered to advertise the pilot event through their own networks, and I sent invitations to all parents who had individually expressed an interest in the ADPS project generally. Particular efforts were made to include deaf parents, as well as hearing parents, and also to include parents from ethnic minority groups. This was intended to inform arrangements for ensuring that the final version was accessible to as wide a range of parents as possible, regardless of linguistic and cultural differences. Those wishing to attend the pilot day were asked to complete and return a proforma, so that crèche, dietary and access arrangements could be adequately arranged.

The pilot day was held on a Saturday and was attended by 24 parents from a wide geographical area, including: Tayside, Fife, Ayrshire, West Lothian, Glasgow and Edinburgh. Six of the parents were deaf, 5 of whom used BSL; one hearing parent used a minority spoken language. As it was known that 9 of the 20 children for the crèche were deaf, two specialist staff were booked, who were fluent in BSL as well as English, in addition to other crèche staff. Access arrangements for the main event included the provision of BSL/English interpreters and an Arabic/English interpreter.

The day was divided into two parts, separated by a buffet lunch. The morning session involved a short introductory session, followed by time for individual completion of questionnaires and of feedback sheets (see Appendix 1 for copy of feedback sheet). It was intended that the afternoon discussion session would focus on issues raised during the morning.

Although it was not possible to collate all the comments in the feedback sheets during the lunch break, a brief perusal of responses showed that most related to difficulties in answering specific questions. Sometimes this was because the circumstances of the respondent did not fit the closed response categories provided, and sometimes because of ambiguities. It was decided that most of these issues could be addressed by re-wording or re-ordering questions, or by adding more open comment options.

The afternoon session was largely taken up by feedback on the morning's experience. It quickly became apparent that completion of the questionnaires had been an emotional experience for some of the parents and an emotionally-charged discussion ensued, with more than one parent in tears. Some of the hearing parents found it a particularly profound experience to meet deaf parents for the first time, and some described the experience as a catalyst in awakening strong feelings about issues around: communication in the family, family services received and their deaf

children's access to activities and family life. An email received from one of the Working Group afterwards included the following comment:

'Focusing on the restricted access that deaf children have to communities/friends/families/extended families etc will always make parents feel sad, upset and, in some cases, angry (I still felt some of these emotions even after all these years), but it reinforces to us the very need for the project.'

As previously planned, the subject of completing socio-economic information was raised by the project team during the discussion. In fact a number of people had indicated, in their individual feedback, that they did not wish to provide socio economic information or had commented that they could not see the point of asking the questions. After explanation of the reasons for inclusion, most agreed that there was sufficient legitimacy in the questions being asked, provided that this was in the context of a clear explanation of why the questions were included, and providing that there was an opt-out for those parents who would find such questions to be overly intrusive. Nevertheless, one or two felt that some parents would still be deterred from completing the forms.

I took responsibility for amending the questionnaire on the basis of feedback received and checking content once more with members of the working group before the final version was printed. The final version contained sections on: identity of respondent; identity and social context of the deaf child; general family information; information about the deaf child; information about language and communication within the home; information about school placement and specialist services; information about the deaf child's personal and social development; income and occupation of parents; and family activities. The full content of the questionnaire is shown in Appendix 16. Questions relating to the data explored in this thesis are included as separate appendices; these will be referred to at relevant points in later chapters.

Validity issues

The design of the instrument, as has been described here, gave primacy to the collaborative process rather than to addressing the questionnaire's psychometric properties, per se. However, arguably, its face validity was tested during the design discussions throughout the collaboration and, particularly, during the pilot stage. It seemed to the working group to be a suitable means of obtaining the kinds of information which we were setting out to collect, bearing in mind the trade-offs and constraints as described above.

The lack of specific attention by the working group to the instrument's psychometric properties, coupled with the aforementioned constraints, undoubtedly compromised content validity in its formal sense. However, it could be again argued that the high level of involvement of representatives of the respondent group in the design, as well as other experts in relevant substantive areas (for example, specialist experienced researchers in the design of questions on independence), ensured some level of guarantee that the content of questions, and the way responses were measured, had validity.

Planning the distribution of questionnaires

The DCS groups had expressed willingness to distribute the Family Survey questionnaires to their networks of parents. However, this would have meant that the survey would have been restricted only to those who were minded to join a DCS group – adding a risk of skewing the representativeness of responses. As described above, the full network of specialist deaf education schools and visiting services were already providing annual information on individual children and young people to the ADPS project. Although it was not feasible to obtain contact details of all parents, for ethical reasons, heads of services agreed to distribute the questionnaires on behalf of the project. This created the potential for a questionnaire to be sent to every family of a deaf child or young person in Scotland, whose deafness was significant enough to be receiving some level of specialist service.

Meanwhile, in order to provide as much personal contact as possible for respondents, I took on the responsibility of co-ordinating a network of volunteer parents, as suggested by the Working Group.

Volunteer network

The initial purpose of the volunteer network was to address one of the main problems associated with a postal questionnaire: the potentially negative effect on response rate of lack of personal contact, as already highlighted. NDCS and DCS representatives suggested that their local networks would provide an ideal source of volunteer parents, who could offer to respond to queries about questionnaire completion, in addition to chasing up parents on their DCS mailing lists. It was hoped that at least two DCS members from each of the 10 local groups would agree to volunteer and three regional briefing sessions were planned. Working Group members were successful in identifying at least two volunteers for six of the ten regions and one for each of the other four. For these four areas, the NDCS national Family Service officer agreed to provide back-up. Two of the volunteers were Deaf.

The briefing sessions, held in Perth, Glasgow and Edinburgh, were designed as training sessions, which implied a didactic role for myself as co-ordinator and trainer. Agenda included: introduction to the draft survey 'pack'; basic information about ADPS; detailed exploration of questionnaire and identification of likely queries; content of a 'crib sheet' for volunteers. In reality, the sessions were more collaborative, with the level of experiential knowledge of attendees being crucial to the development of materials for the volunteer network and thus my role being more of a facilitator than a trainer. Out of a possible 23 volunteers, 13 were able to attend the sessions. The others were contacted individually, either face-to face, by telephone and/or by email.

The final version of the volunteer pack included:

- A brief description of the role of the volunteer and 'if in doubt' contacts
- Volunteer guidelines (model responses for likely questions)

- Description of types of professionals listed in the questionnaire
- Free-phone NDCS helpline number to pass to parents for queries other than those which were questionnaire-related

The 'Survey Pack'

The final version of the individual 'survey pack', to be distributed to each family of a deaf child in Scotland, included:

- A covering letter
- The questionnaire
- Brief invites for users of other languages to apply for more information
- Contact details for local volunteer
- Brief information on ADPS
- A prize draw entry

See Appendix 2 for copies of items included in the pack.

Following Cohen et al., (2000), within the covering letter, direct reference was made to confidentiality of answers and the letter was kept to one page in length.

Distribution

In order to maximise the chances of services carrying out the distribution, tasks required of deaf education services were kept to a minimum: questionnaires, and accompanying information, were packed by ADPS staff and volunteers into sealed, freepost envelopes and each questionnaire was coded to indicate relevant local authority. Services were asked to label and post the packs.

As it was late in autumn term, it was agreed with heads of services that distribution would be held back until after the Christmas holiday period, following advice from Cohen et al. (2000:112) to 'avoid at all costs a December survey'.

The delegation of distribution did have the disadvantage of the project losing control over the number of questionnaires actually sent out. Maintaining the good will of the services was vital to the continued collection of pupil data, so there was a limit to the amount of pressure which could be put on all 52 services to provide details of numbers of questionnaires posted. Sixteen hundred questionnaires were sent out to services for distribution. Numbers of packs per service were decided on the basis of the number of pupils from respective services on the ADPS database from the previous year's data collection – plus extra to take account of the fact that the numbers were bound to vary from those of the previous year. The additional families were likely to be those who received a service level lower than that which triggered the establishment of a record (ie, less than two visits per year from a teacher of deaf children).

The fact that distribution was delegated also meant that it was not possible to contact parents direct with a reminder letter, as recommended by Cohen et al. (2000). Due to the extent of pressure already put on services to complete the pupil survey, it was decided that they would not also be asked to undertake a reminder mail-shot. However, in addition to personal contact from DCS volunteers, it was hoped that those who were NDCS members would see the reminders in DCS and NDCS newsletters

Access arrangements

As previously noted, it had been agreed that access arrangements would be made for those whose first language was not English. A BSL video translation of the covering letter was filmed, presented by one of the Deaf parent volunteers, and a spoken language interpreting agency was consulted about translations into minority spoken languages.

The survey pack contained an invitation for respondents to request the BSL video translation of the covering letter. Twenty seven videos were requested and dispatched, including a few requested direct from schools for inclusion with

questionnaires to known users of BSL. The video also explained, in BSL, how parents could get further assistance with questionnaire completion, by contacting one of the local volunteers on the relevant list within the survey pack. As two of the volunteers were Deaf themselves, they could provide face-to-face assistance in BSL, if within reasonable travelling distance. Where hearing volunteers who did not have advanced level BSL received email or text request from Deaf parents, arrangements were in place for them to make a home visit with a BSL/English interpreter. There were no requests for this service.

The pack also contained short paragraph about the survey in each of the four most common minority spoken languages, inviting them to return a form indicating that they wished to complete in their own language. In these cases, a volunteer could be contacted, who would arrange a home visit with an interpreter of the relevant spoken language. Urdu interpreters were twice booked to translate volunteer/parent visits.

Response

Response rate

420 completed questionnaires were received. The vast majority were completed by mothers (90%) with 8% completed by fathers and a small number completed by others, including: mother, father and deaf young person together

Table 2.1: Parental status of respondents

| Completer of survey | Frequency | Percent |
|----------------------------|------------------|----------------|
| Mother | 377 | 90 |
| Father | 35 | 8 |
| Other | 8 | 2 |
| Total | 420 | 100 |

The fact that services acted as distribution gatekeepers caused problems in identifying an accurate distribution total, and meant that there are difficulties in ascertaining a precise response rate. In particular, although we were able to identify the fact that some returns were received from all but two very small local authorities, there were very low numbers of returns from some areas which had more than one service or school, suggesting that some services did not distribute. We were, in fact, made aware months later of two services which had not distributed the forms, due to other pressures at the time, and there may have been more examples of this.

A further complication was the fact that the number of questionnaires sent to each service was determined by using the Group A figure from the previous year (2002/03), with the addition of an extra number of forms (the distribution date was in advance of the ADPS 'census date' for 2003/04). As it transpired that the parent contact lists used by services to distribute the questionnaires were likely to vary slightly from the lists of pupils reported by services as being within the ADPS 'Group A' remit (as described in chapter 3), this meant that neither the number of forms sent to services, nor the Group A totals for 2003/04, could be taken as being a precise distribution figure.

Bearing all of this in mind, the total population of 'Group A' in 2003/04 was 1423. If this is taken as a proxy distribution level, the resulting proxy response rate is 30%. In view of the fact that not all services distributed the forms, it should be born in mind that this figure is likely to be slightly conservative.

Despite this proxy rate being low, even when taking into account that it is likely to be a slight under-estimate, it is not untypical of other similar surveys (Gillham, 2000). In fact the returns were favourable compared to two other recent surveys, which targeted parents of deaf children. A UK-wide survey on deaf education, conducted by the Royal National Institute for Deaf People, which was aimed at professionals and deaf adults as well as parents, received only 271 parent returns (Gregory et al., 2001). Similarly, a recent UK-wide NDCS survey of deaf young people and their parents attracted 255 parental responses, 12% of which were

from Scotland (NDCS, 2008). Neither of these studies published a distribution total, nor, consequently, percentage response rates. However, both aimed to reach total populations and so, in each case, the responses are very low compared to the potential populations of families of deaf children in the UK. The British Association of Teachers of the Deaf 2003 survey reported over 18,000 children with a hearing loss in England alone (BATOD, 2003).

Although the volunteer network was contacted by potential respondents less than expected, in relation to advice over completion of the forms, individual volunteers did receive a number of calls: five parents thought that their child's hearing loss might be too mild to warrant completion of the questionnaire; two had more than one child and so were requesting additional forms and one had read information about the survey but had not received a questionnaire, so asked for a form. Only one person requested advice in completing the form; in this case the volunteer reported that she spent an hour providing telephone advice. In another case, a parent had wrongly assumed that her name and address had been given out by the school and had phoned to complain – to be reassured by the volunteer that this was not the case.

However, overall, the response was still undoubtedly lower than hoped for, particularly given the efforts to ensure a high rate of returns.

Possible reasons for low responses

Although resources did not permit intensive interview follow-up of both respondents and non-respondents, as suggested by Cohen et al. (2000), it is possible to surmise some of the most likely reasons for the low response, in addition to the implications of delegated distribution, as already discussed.

We were made aware of the fact that some services distributed questionnaires very late, due to particular pressures on time. Apart from confusion which may have been caused by an apparently out-of-date covering letter, any incentive impact of the prize draw would have been negated. For example, in one local authority with a

single service, a long delay was due to change of management at the time they received the batch of questionnaires. Only 2 responses were received from the area, representing only 9% of the 19 deaf children and young people in that area known to the ADPS project at the time.

Cohen et al. (2000) suggest that a series of three reminder letters are sent in postal surveys, and that this can increase the original return by as much as 30%. However, this reminder process would have had to be delegated to services and, as has already been indicated, it was decided that this would have put undue pressure on them. Although efforts were made to remind parents about completing the questionnaires, this was done through NDCS and DCS parent newsletters - thus restricting the distribution of reminders to those who were on respective membership lists. Also, although the expectation had been that the volunteer network would make reminder phone calls to the parents on their mailing lists, again their lists excluded parents who were not NDCS members. Furthermore, it transpired that there were various practical problems among the volunteer network, which meant that less chase-up calls were made generally than had been hoped.

Issues raised as potentially problematic may still have caused barriers, despite efforts made to reduce potential difficulties. Thus, the inclusion of sensitive information, such as parental income and educational levels, religion etc, which may have been construed as overly intrusive, may have put some people off completion, as predicted by some of the parents in the development of the instrument. Similarly, questions which could be construed as having a socio-cultural bias may have alienated some parents – again as discussed within the Working Group. Also, despite efforts to make the questionnaire accessible, and help being offered with completion, some people are still likely to have found the written text throughout the survey pack prohibitive, and may well have found it too embarrassing to ask for help from other parents through the volunteer network.

Finally, there is some evidence that the length of the survey instrument can be a factor in response rate (Bogen, 1996). Although evidence is inconclusive and not

specific enough to indicate a winning formula, it may be that a shorter questionnaire might have motivated more people to complete it.

Impact of low response

The low rate of return limits the extent to which the findings can be seen as representative of perceptions of parents of deaf children generally, as it is not possible to further explore the characteristics of the respondent group compared to those who did not respond. Consequently the responses can effectively be viewed as a non-probability sample, with the resultant limitations to generalisability which this indicates (Bernard, 2000:175). However, it is possible to compare key demographic data of the parents concerned, and of their deaf children, with wider population profiles, in order to help to establish the extent to which the sample can be viewed as representing the target population. This exploration is undertaken in chapter 3.

Analysis

This section begins with a description of the methods by which data was analysed. Following this, implications of the fact that the development of research questions, and the application of symbolic capital as a theoretical framework, were undertaken after the data was collected are addressed, as well as the extent to which the analysis can be described as secondary rather than primary. Finally, methodological issues pertinent to the validity of the analysis of the qualitative data are discussed: the influence of personal professional standpoint on the categorisation of qualitative data; an exploration and justification of the way in which qualitative data was, effectively treated quantitatively during analysis; and implications of the low proportion of respondents who provided qualitative data.

Methods of analysis

As described, the questionnaire contained both closed and open questions and therefore analysis involved both quantitative and qualitative approaches.

All questionnaire responses were inputted into a Filemaker database. This was undertaken by a small team of experienced data in-putters, with a proved track

record in accuracy. Checking was done myself, both by sampling, after completion of the process, as well as frequently throughout the whole process of analysis, whenever there was an indication of possible anomaly.

After the data was inputted, I was responsible for exporting relevant fields into Excel and into an SPSS statistical software package, where I created independent variables (such as age, hearing loss level etc) and dependent variables (such as level of reported quality of communication) for analysis.

Other variables were constructed by myself during the course of analysis; some were created after coding data which had been reported in open questions (for example: languages used; ethnicity; physical and learning difficulties etc), and others by amalgamating categories (such as age; school year of deaf children of respondents; deaf/hearing friendship permutations and difficulties in accessing activities).

Due to the low response rate, demographic profiles of respondents and their deaf children were first compared to those in comparator populations, and statistical indications of representativeness calculated by use of chi-squared testing, as will be described in chapter 3. The decision to focus on the group defined by the same criteria as those determining 'Group A' within the ADPS pupil database is explicated within the same chapter.

Due to the variety of restrictions to generalisation of data, statistical exploration of quantitative data was limited to descriptive analysis. One significant reason for this is the low numbers of cases when the data were broken down into sub-categories.

Qualitative data provided by respondents in the form of open comments were manually coded thematically by myself. This process involved producing and exploring lists of comments for each open question. I then personally identified and constructed emergent themes. Although the comments were usually brief, the

exercise was essentially interpretative; it therefore should be seen in the context of relevant elements of my own standpoint which could be construed as having any potential influence on the outcome of categorisation. Consequently, details of my standpoint elements are explicated later in this chapter.

Dependent variables representing the inductively-constructed codes were created in most cases, in order to represent the extent of commonalities among comments (bearing in mind the implications of treating such qualitative data in a quantitative way, as is discussed below). Direct quotes from comments are used throughout findings in order to: illustrate trends and idiosyncrasies; bring depth to the statistical findings, and reduce the extent that the researcher was interpreter/gate-keeper of the meanings of respondents' contributions.

Influence of the theoretical framework

The theoretical framework was identified as appropriate during the process of devising the research questions and therefore it was an influence on the analysis process. For example, the choice of framework acted as endorsement of the selection of specific questionnaire sections/questions as data sources, such as: language and communication ('linguistic capital'); friendships and social activities ('social capital'); attendance at cultural events ('cultural capital') and sporting activities ('physical capital'). It also helped to provide a steer for the way that findings were categorised, framed and presented; for example the focus on bonds and networks in the section on friendship patterns and the pursuance of comparison between children of deaf parents and those of hearing parents.

However, it was in the interpretation of the data that the influence of the theoretical framework was most significant, underpinning the structure within which key findings could be presented, the choice of which findings were to be privileged and the nature and direction of discussion and conclusions.

Secondary or primary data analysis?

The fact that the data was not gathered specifically for this thesis may imply that the analysis used in this study is of a secondary rather than a primary nature (McCaston, 1998). However, for the following reasons the process could more accurately be described as the ‘analysis of secondary data’ rather than ‘secondary data analysis’:

- I had particular responsibility for the collection of the Family Survey data;
- no data from this survey has previously been published;
- the application of the theoretical framework was, as described above, post-hoc (and therefore, to some degree, being analysed for a different purpose to that which drove the data collection).

Certainly, one of the main advantages of secondary data analysis is relevant: that it allows for the analysis of a larger scale study than would normally be possible within doctoral study (McCaston, 1998). In the case of exploration of the Family Survey, the cost and other resources involved would have been prohibitive – particularly in view of the intention to link to a larger dataset.

As already noted, the Family Survey project was approved by the Ethics Subcommittee of the Moray House School of Education Research Committee. Information given to parents within the survey pack about the purpose of the project does not preclude analysis for this thesis. The NDCS, as the main collaborator in the survey process, has specifically approved this use of the survey, as a means of exploiting an aspect of the data which otherwise would remain unexplored. This is particularly important in the light of the fact that one of the main aims originally was to inform service development.

Influence of professional standpoint

Although I am a qualified teacher of deaf children, and have experience of working with deaf children within school settings, a substantial part of my initial professional employment within the field of deaf education, including the initial

years, involved working with families, as well as providing specialist support and access within further and higher education sectors. In these sectors, linguistic diversity of access, support and social life is taken for granted, and I often encountered problems attributable to the limitations in the diversity previously offered to individual students (and their families) when they were at school.

These experiences, as well as years of contact with a wide diversity of D/deaf colleagues, have laid the foundation of a personal standpoint which, as already noted, coincided with other members of the ADPS team. To repeat, this standpoint includes cultural and linguistic elements in its conceptualisation of deafness, considers that the linguistic spectrum offered to deaf children and their families should not exclude BSL, and views D/deaf networks in positive terms – as alternative networks for deaf people of all ages.

The fact that I was solely responsible for categorising the open comments made by respondents should be seen in this context. It could be construed, therefore that I, as researcher, could have privileged themes and interpretations relating to my own standpoint. I have aimed to counterbalance this by transparency: extensively quoting examples of comments both within the thesis and in relevant appendices.

Quantitative treatment of qualitative data

I have suggested that the inclusion of both closed and open survey questions sits within a critical realist perspective. Such a perspective places value on knowledge constructed by the kind of quantitative measurement applied to data from the closed questions, as well as knowledge constructed from qualitative data derived from responses to the open questions. According status to even such limited qualitative data demonstrates the inclusion of an interpretive position – that is, that knowledge relating to human behaviour is to some extent socially constructed and multi-dimensional in nature (Denzin & Lincoln, 2000). While there is a lack of consensus as to what constitutes validity and reliability within qualitative research, addressing the complexities of multi-dimensionality is fundamental, including such factors as reflexivity and depth (Silverman, 2000). Therefore, by categorising

comments, and by according import to the frequency of instances within a given category, it could be argued that this quantitative treatment rather glibly compromises the validity of the analysis of comments; essentially I have assumed that the perceived commonalities are sufficiently one-dimensional to measure by simply adding up instances within the constructed themes.

Also, it should be pointed out that, had the respondents been interviewed, it would have been possible to explore the meaning of comments made. Without this opportunity, I have had to take the comments written by respondents at face value.

Furthermore, fewer than a third of respondents ever made open comments in any one question, and the characteristics of those who did provide qualitative data were not explored. Therefore it is not possible to say how representative they were of the respondent group as a whole.

However, whilst fully accepting the limitations of these factors, I suggest that there is still value in highlighting the commonalities discovered, in terms of bringing richness to the descriptive statistical findings and in terms of signposting areas for further research – particularly bearing in mind that representatives of the respondent group were co-designers of the instrument.

Therefore, while I have highlighted within this chapter a number of ways in which there are limitations to the validity of the process of analysis of secondary data, and to the data themselves, I have argued that the level of validity is such that the data can provide a useful contribution to knowledge and pointers towards further study.

A number of specific challenges experienced during the data analysis process will be addressed at relevant points throughout the chapters which focus on findings, and summarised at the beginning of chapter 6. However, before going on to explore findings, the next chapter will focus on the extent to which the sample used for analysis can be seen as representative of comparator populations.

Chapter Three: Sample Representativeness

As explained in chapter 2, it was necessary to compare the demographic profiles of the survey respondents, and their deaf children, with relevant wider populations, in order to assess the degree to which the sample could be viewed as being representative of the target population: all parents of all deaf children in Scotland. As noted in chapter 1, previous research has shown that a number of factors are likely to affect deaf children's educational achievements and social inclusion. Some of these are common to hearing children, such as specific learning difficulties, and parental socio-economic status; some are more specifically related to deaf children: for example, level of deafness and parental hearing status. As far as possible, such factors have been included in demographic profiles explored in this chapter.

In the first part of this chapter, demographic data about the deaf children of respondents is compared with data from the ADPS pupil survey, except for the case of data on hearing status of siblings where a different comparator is used, so that the profile of the sample can be compared to that of all deaf children in Scotland. An argument is made for comparing the profiles of two sub-samples within the Family Survey ('Group 1' and 'Group 2'), in order to isolate those who came within the criteria of the comparator ADPS population. Categories of information explored include: geographic location; age; gender; hearing loss levels; physical and learning difficulties; first language; ethnicity; and school placement.

Most of the information collected in the Family Survey relates to the deaf children of respondents. However, details on parents' socio-economic status and hearing status were both gathered. Therefore, in the second part of this chapter, socio-economic data on respondent parents is compared with similar information relating to the nearest available comparator data within the Scottish population, in order to ascertain to what extent the Family Survey household profile is similar to that of Scottish parents generally. In terms of parent hearing status, data is compared

with information from the USA, as there is no equivalent Scottish or UK-wide data in this area.

The two Family Survey sub-samples, Groups 1 and 2, are compared for all data relating to parents. An argument is made for focusing solely on findings relating to the Group1 population for the rest of this thesis.

Other than for age distribution, the extent to which the sample is representative of the comparator populations will be calculated by the application of chi-squared testing. Unless otherwise stated, the distribution will be considered as significantly different where the probability is calculated as less than 0.05 ($p < 0.05$).

Demographic profile of deaf children of respondents

‘Group 1’ and ‘Group 2’

As described in chapter 2, the ADPS remit included all preschool children, but the pupil population was defined by the level of service received. The assumption behind this strategy was that, by including all those who attended specialist school provision, or who received two or more visits per year from a specialist teacher of deaf children, this would mean that all those pupils whose hearing loss was significant enough to impact on education would be encompassed. These pupils became known within the project as ‘Group A’. Visiting services also kept information on those pupils who were visited once a year, or who were on dormant lists (for example, where a pupil had a fluctuating hearing loss). It was not practical for ADPS to ask services to provide detailed information on these pupils, but very basic aggregate information on hearing loss level and school level was collected in the first two years of the project. These were known as ‘Group B’ and, as might be predicted, the vast majority of these had relatively slight hearing loss levels.

It had been assumed that Family Survey questionnaires would be completed by parents of children who had ADPS records and that, therefore, it would be possible to connect to data in the pupil database: for example, for audiological detail. However, it was discovered, during the inputting stage, that a number of deaf children of respondents did not have an ADPS record. After following up individual cases with parents or relevant services, hearing loss levels were established for the vast majority. It transpired that a few of these cases actually fell within the Group A remit, but, for various isolated reasons (or, in some cases, simply inexplicably), ADPS pupil survey returns had not been submitted by services. For the purposes of this study, they have been classed as 'Group 1', along with the other ADPS-recorded Group A cases. All the cases which do not have ADPS records, and do not clearly fall within the ADPS remit, have been classified as 'Group 2'. These 54 cases include one preschool child with a mild loss, who was not receiving a service at all at the time of the survey, and 16 cases of pupils with no ADPS records for whom it was not possible to ascertain their eligibility for Group A.

It was necessary to explore the distinct profile of the 'Group 2' cases, in order to decide whether it was appropriate to include the data for them and their families in the findings of this thesis. This was because the comparator data of the national population in Scotland comprised pupils within the ADPS pupil survey remit. Therefore, in the following subsections, four groups will be compared: Group 1; Group 2; Total Family Survey population (Group 1 plus Group 2), and ADPS national population. Data profiles for Group 2 are likely to be more idiosyncratic due to the relatively small number of cases.

Age profile

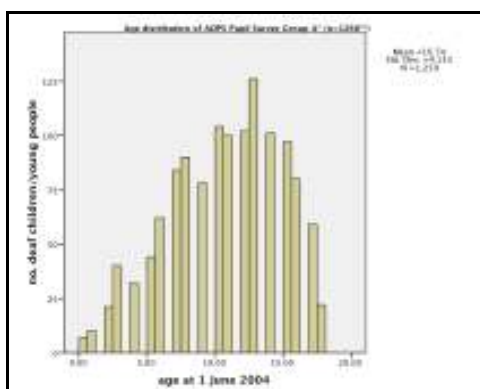
The age profile of the deaf children of respondents, compared to that of all deaf children in Scotland, in the same year, is illustrated in charts 3.1 (a-d). It can be seen that the profile of the total Family Survey population (Group 1+2, chart 3.1d) is closer to that of the national population (chart 3.1a) than that of either the Group 1 or the Group 2 population. In both 3.1a and 3.1d, the majority of the children and young people concerned are clustered around the 8 yrs to 15 years age range (upper

primary and lower/mid secondary age). The mean age of both groups is between 10 and 11 years, with a standard deviation from the mean of just over 4 years.

Charts 3.2 (a-d) demonstrate that the school level profiles of both Group 1 and Groups 1+2 are similar to that of the national population, whereas the dearth of preschool children in Group 2 makes its profile noticeably different. Group 1+2 is not significantly different to the ADPS population, while Group 1 is significantly different, due to a slight skew towards preschool age. Therefore, this will need to be borne in mind, wherever relevant, when reporting findings.

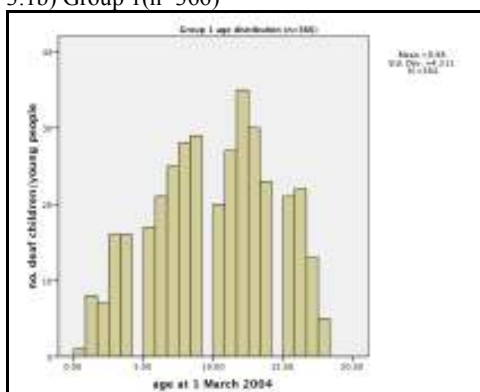
Chart 3.1(a-d) Age distribution of ADPS Group A and of deaf children of respondents

3.1a) ADPS Group A (n= 1260)



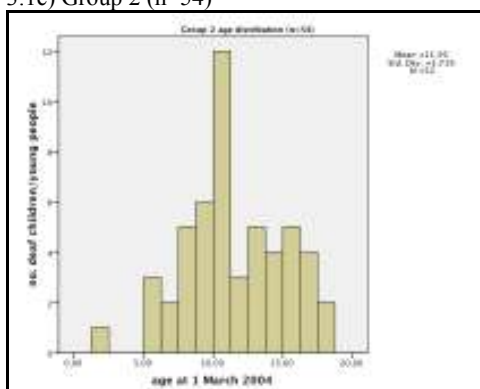
(mean age 10.74; standard deviation 4.13)

3.1b) Group 1(n=366)



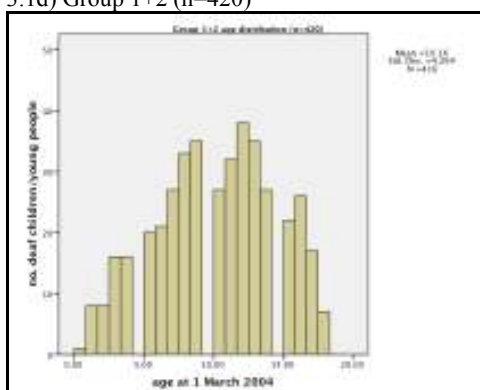
(mean age 9.98; standard deviation 4.3)

3.1c) Group 2 (n=54)



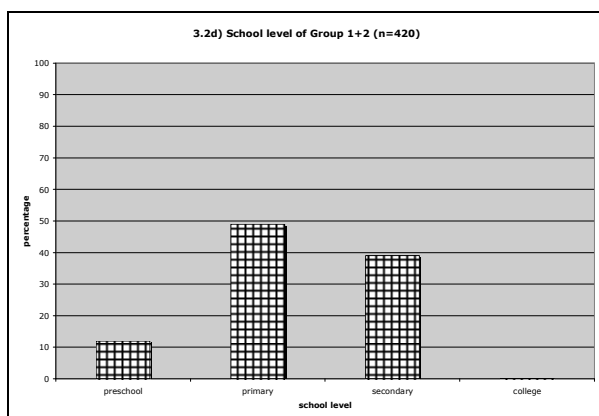
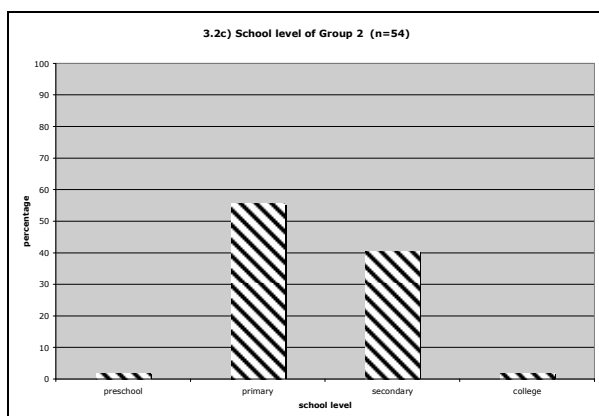
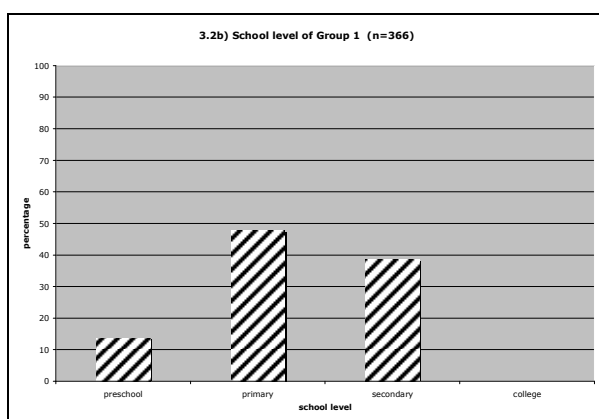
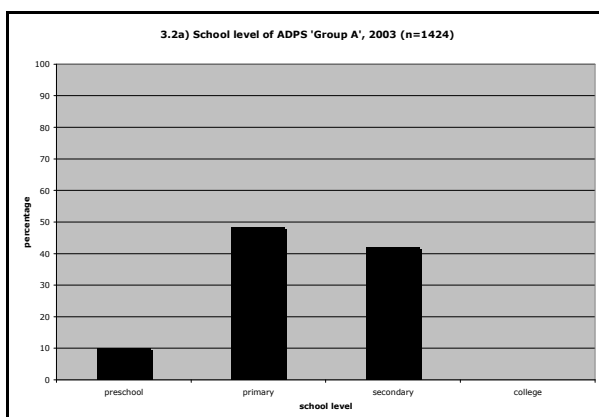
(mean age 11.39; standard deviation 3.6)

3.1d) Group 1+2 (n=420)



(mean age 10.16; standard deviation 4.26)

Chart 3.2 (a-d) School levels of ADPS Group A and of deaf children of respondents

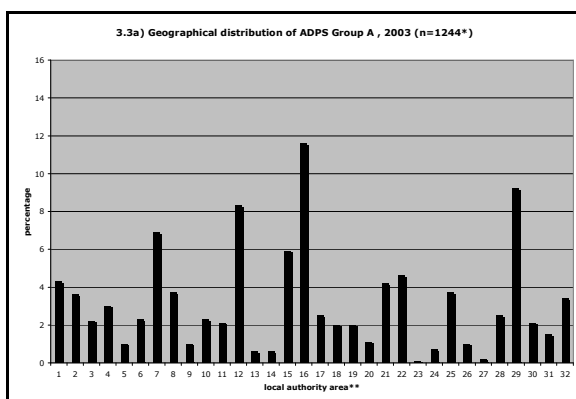


Geographical distribution

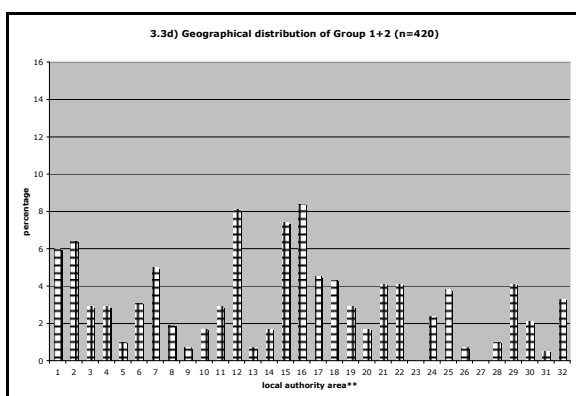
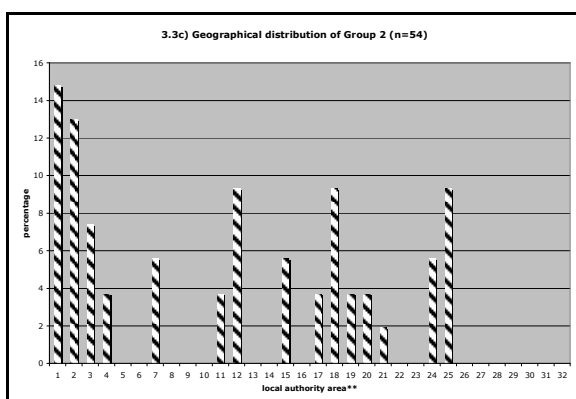
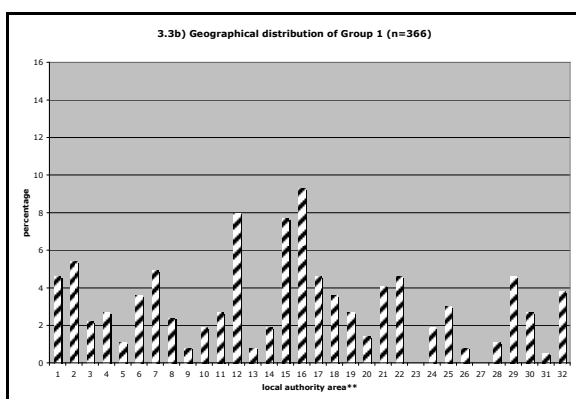
Charts 3.3d shows that the total Family Survey sample is distributed throughout nearly all local authorities in Scotland. Whilst there are no deaf children/young people from two of the smallest local authorities, chart 3.3a illustrates the fact that, even among the ADPS records, there are less than 1% in each of these areas. Other differences can be noted in terms of the size differentials between the two sub-populations in specific local authority areas. In particular, there is a noticeable degree of Family Survey under-representation apparent in the urban areas of 16 and 29 and a mix of smaller degrees of over-representation and under-representation in other areas. Due to the breadth of distribution, and the small numbers in each category, chitesting was not undertaken on this data. However, overall, there appears to be a reasonable level of geographical spread, and thereby representativeness, within the Family Survey population.

In terms of differences between Groups 1 and 2, the population of Group 1 is very similar to that of the total Family Survey sample (Group 1+2), whereas that of Group 2 is concentrated in less than half (15) of the 32 local authorities.

Chart 3.3 (a-d) Geographical distribution of ADPS Group A and of deaf children of respondents



* unpublished ADPS data (based on 88% return)

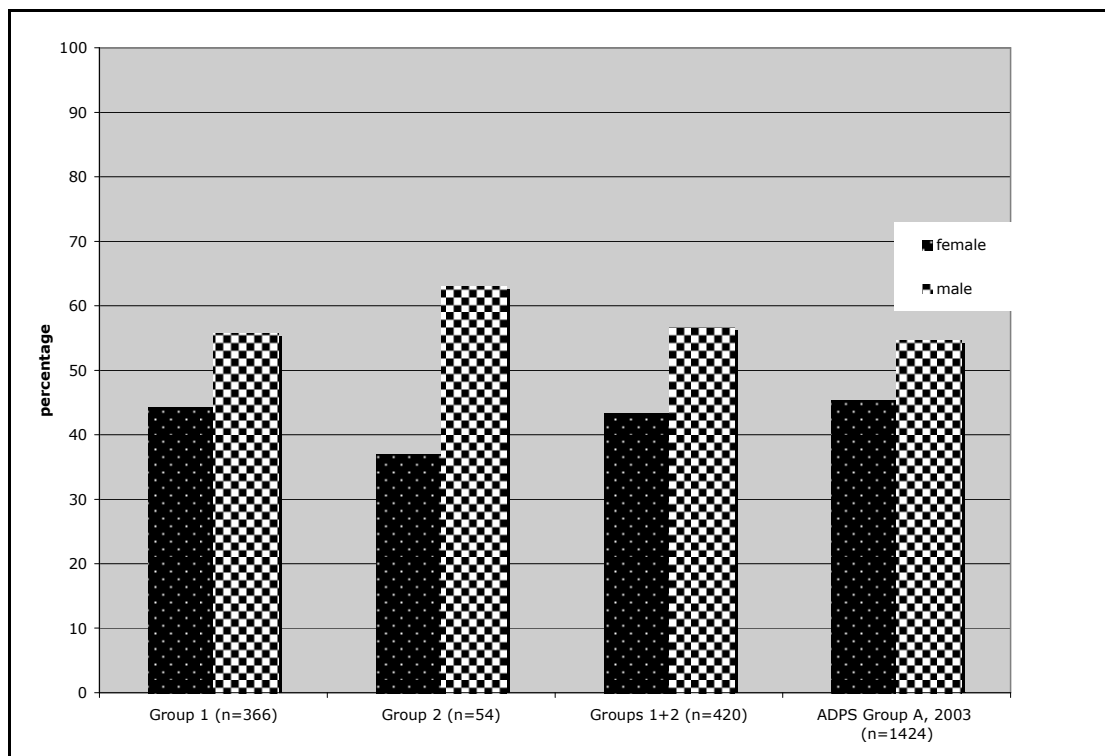


**numbering is consistent among the charts, but the allocation of numbers to local authorities was random, for the purposes of anonymity

Gender profile

Data from previous American and UK large-scale studies have indicated a degree of gender difference among deaf children, with more boys tending to be reported as being deaf than girls (Fortnum, Marshall, Bamford, & Summerfield, 2002; Kluwin, 1994). The overall prevalence within the US population was calculated at 10.5% for males and 6.8% for females, and the percentage of males in Fortnum et al.'s UK study was 54% compared to 46% girls. Chart 3.4 shows the same gender characteristic within both Family Survey and ADPS Group A pupils, and statistically, neither Group 1 nor Group 1+2 is significantly different from the ADPS population.

Chart 3.4 Gender of ADPS Group A and of deaf children of respondents



Hearing loss levels

Construction of audiometric descriptors

The ADPS pupil survey collected detailed audiological information on deaf preschool children and Group A school pupils. Teacher respondents provided, for left and right ears, information on ‘unaided’ (ie without hearing aids) decibel (dB) hearing threshold levels along a standard range of frequencies. The database automatically calculated a hearing loss banding, or ‘audiometric descriptor’, using the formula recommended by the British Society of Audiology (British Society of Audiology, 1988). The formula dictates that the banding is constructed from the average threshold reading, across the standard frequencies. Where the hearing loss is bilateral, the descriptor is based on the ‘better ear’ average threshold. Conventional descriptors are: ‘profound’; ‘severe’; ‘moderate’; ‘mild’.

ADPS also created two additional categories: ‘cochlear implants’ and ‘within normal limits’. The cochlear implant category was constructed to take account of the fact that there is not universal agreement as to how implanted children’s hearing loss should be categorised. On one hand, the implant is more permanent than a sophisticated hearing aid, and therefore there may be an argument for using thresholds relating to readings taken when the implant is switched on. However, when the implant is disconnected, the child or young person will be very deaf, and so there is a counter-argument that the implant should be classed as a hearing aid - and that, therefore, the descriptor could be based on readings taken when the implant is disconnected. Consequently the ADPS team pragmatically decided that implanted children would be separately categorised (Grimes, 2005). The ‘within normal limits’ category was created to take account of the fact that some children may have a bilateral hearing loss, but still have a ‘better ear’ average threshold below that of the ‘mild’ banding.

The simplicity of the formula means that the complexities of real-life hearing functionality are not always reflected in the resulting descriptor for some pupils. For example, a child may have profound hearing loss in one ear and a high frequency loss in the other ear, leading to a particular barrier in deciphering speech; however,

the descriptor may be constructed as ‘moderate’, suggesting a greater ease of hearing speech than is really the case. Where a teacher indicated that such an anomalous situation had occurred, this was recorded in the ADPS database, so that there was an option to override the calculated banding with a more functional descriptor. There was only one example of this in the data which was exported from the pupil database to the Family Survey records. In this case the override descriptor was exported (‘severe’ rather than ‘moderate’).

In the case of Family Survey responses where there was no corresponding ADPS pupil record, whenever possible, a descriptor was allocated from discussion with parent and/or specialist teacher of deaf children. In these cases the descriptor proffered was usually based on the standard formula, as described above, which is routinely applied within services in order to categorise hearing loss levels.

It was not possible to obtain the hearing loss level in 39 cases. Ten of these related to preschool children and eleven to children with learning disabilities; both are groups where it is known that identification of hearing loss thresholds can be difficult.

Hearing loss level profile of respondents’ deaf children

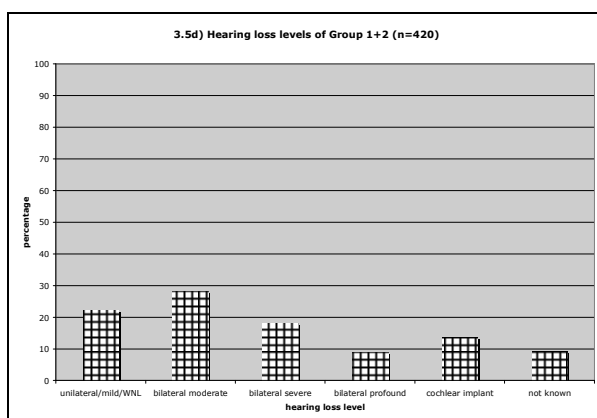
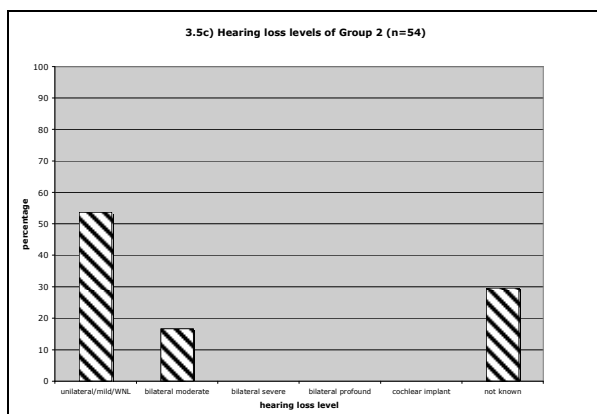
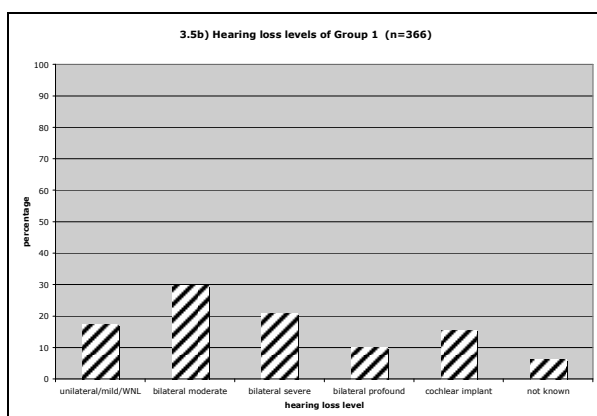
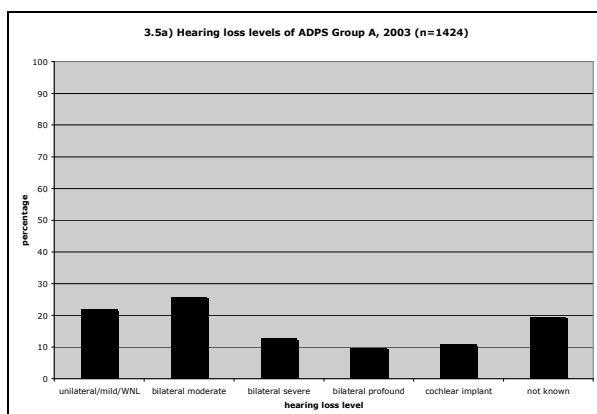
The hearing loss profile of Group 2 is, as expected, heavily biased towards relatively slight hearing loss levels, as chart 3.5c shows. The majority (54%) had mild/unilateral/‘within normal limits’ losses and only 9 (17%) had a moderate hearing loss. This confirms the likelihood that, in these cases, the slight level of hearing loss was significant to the low level of service received, and thus the fact that these pupils had been deemed by teachers respondents to be outwith the ADPS pupils survey Group A remit.

The profiles of Group 1 and of Groups 1+2 are very similar to that of the ADPS Group A population, with Group 1+2 being closest in pattern (chart 3.5a, b and d). A comparison of the latter group (chart 3.5d) with the ADPS national population (chart 3.5a) reveals that there is a spread of cases across all hearing loss

categories, with the largest proportion being in the ‘bilateral moderate’ category. The total Family Survey population has a smaller proportion of ‘not known’ levels, balanced by slightly higher proportions in both the ‘bilateral severe’ and the ‘cochlear implant’ categories. When the ‘not known’ group is disregarded, statistically, the Group 1 distribution shows significant difference from the ADPS population, due to the skew towards severe and implanted categories.

Therefore, when findings from the Group 1 population are considered, the bias towards these categories of hearing loss will need to be taken into account, where relevant.

Chart 3.5 (a-d) Hearing loss levels of ADPS Group A and of deaf children of respondents



School Placement

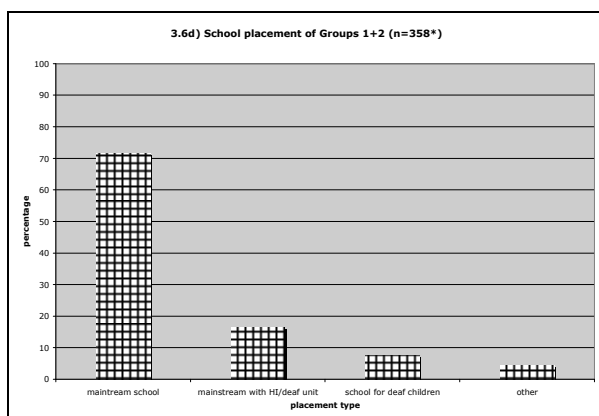
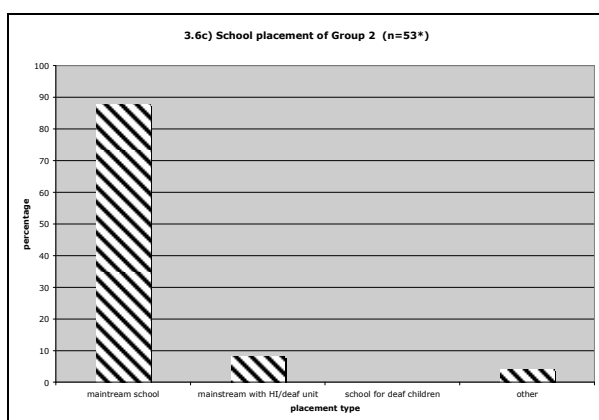
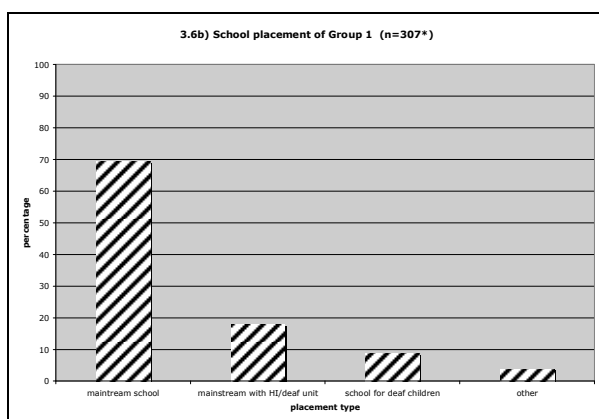
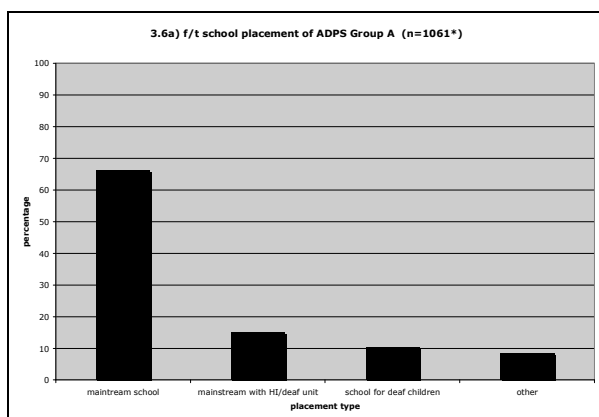
The vast majority of school children in the sample were attending mainstream school, reflecting the ‘inclusion’ trend in legislation and policy (Great Britain, 1980; Riddell, 2002; Scottish Parliament, 2000). Current legislation presumes mainstream placement for all children, with special school placements only being provided under special circumstances as set out in the Standards in Scotland’s Schools etc Act (Scottish Parliament, 2000).

Chart 3.6 (a-d) illustrates this dominance of mainstream placement among the Family survey population and sub-populations, as well as within the full-time school placement profile of the national ADPS ‘Group A’ population of deaf children in the same year.

The only profile among the four which stands out as markedly distinct is that of the Family Survey Group 2 3.6c, which is predictably different. The proportion of this group in mainstream placement is notably higher than the others (almost 90%), and no pupils among this group are in schools for deaf children. This undoubtedly relates to the fact that a particularly high proportion of these pupils have relatively slight hearing loss levels, as just described above.

Despite the apparent similarity of patterns in distribution between ADPS pupils survey population and that of both the Family Survey Group1+2 and Group 1 populations, statistically they are both significantly different, with Group 1+2 showing most difference. This is due to a slight skew, in both Family Survey populations, away from schools for deaf children and ‘other’ placements and towards mainstream placements. This will need to be taken into account when considering the effect of school placement in the analysis of findings.

Chart 3.6 (a-d) School placement of ADPS Group A and of deaf children of respondents



* total cases where relevant information was provided

Incidence of visual impairments, diagnosed medical conditions, and physical and learning difficulties

As with hearing children, the presence of specific disabilities may affect a deaf child's capacity for learning. Various large-scale studies have collected data of this nature among populations of deaf children, and found levels varying from 30% to 40% (Fortnum, Davis, Butler, & Stevens, 1996; Fortnum et al., 2002; Gallaudet Research Institute, 2001). Such levels of 'additional disabilities' are usually portrayed as implying that there are higher than average levels of learning disabilities among populations of deaf children. While this well may be the case, there are reasons for caution. Firstly, the very broad range of conditions, syndromes and difficulties encompassed may include difficulties which have arisen from environmental factors, such as inappropriate linguistic environment, rather than being intrinsic to the child. This is most likely to occur under headings such as 'speech and language' or 'learning difficulties'. Secondly, they may also include conditions which may have no, or minimal, impact on learning (for example, allergies or asthma). Finally, there do not appear to be any large-scale collections of similarly detailed data among the hearing population and therefore no clear means of comparison.

Therefore, the intention in this study was to ensure that information provided by respondents about any disabilities and medical conditions pertaining to their deaf children was carefully coded to reflect likely impact on learning. This meant that the presence of a barrier to learning, rooted in the occurrence of a medical condition, syndrome or specific difficulty, could be factored most meaningfully into thesis findings.

There were three relevant subsections within the Family Survey: diagnosed visual impairments (VIs); diagnosed medical conditions, and diagnosed specific learning difficulties. Examples of the latter were provided within the survey question (autistic spectrum disorder; asperger's syndrome; attention deficit hyperactivity

disorder; dyslexia; social, emotional and behavioural difficulties and dyspraxia). Each sub-section requested both name and level of condition(s). Unfortunately, due to the pressure to save space in the design of the survey instrument, an initial yes-no question for each of the three subsections was omitted. Consequently, where a subsection has been left blank, although it is highly likely that this is an implicit 'not applicable' report, it is not possible to be absolutely certain that this is the case. For the purposes of coding, no response to a subsection has been taken to mean 'not applicable', as indicated in reports of findings below.

Relevant ADPS pupil survey data had already been coded according to categories constructed by an ophthalmologist and consultant paediatrician with particular responsibility for deaf children, both of whom also were involved in coding the pupil data for 2000/01. Table 3.1 shows how these codes were constructed. It was acknowledged at the time that there were limitations to the exercise because the data was provided by teachers rather than by medical practitioners. Bearing this in mind, it was still felt to be a useful indicator of likely impact on learning.

Table 3.1: ADPS constructed categories for reported medical conditions, physical and learning disabilities

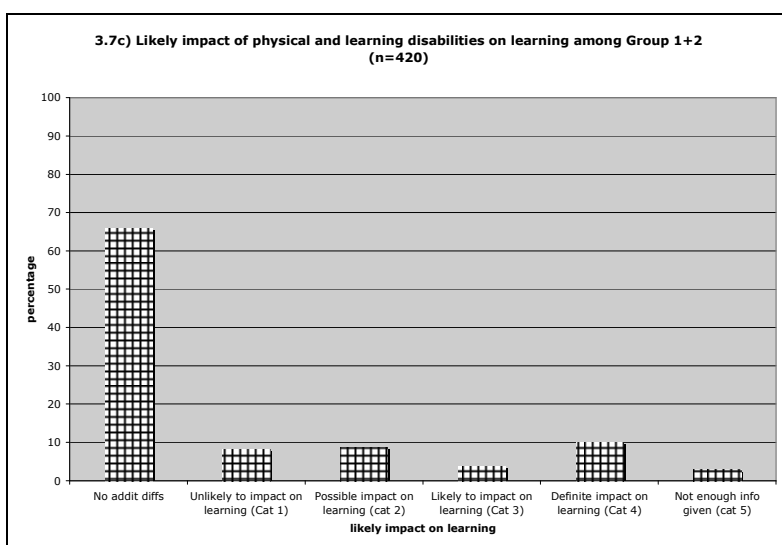
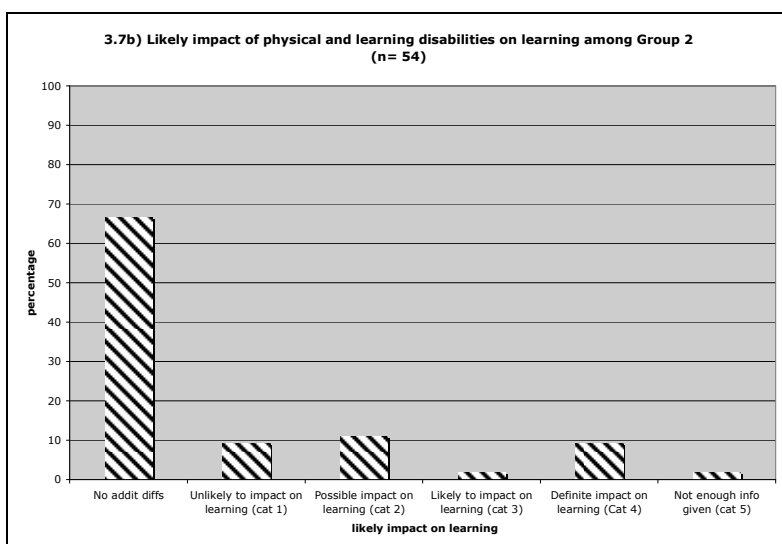
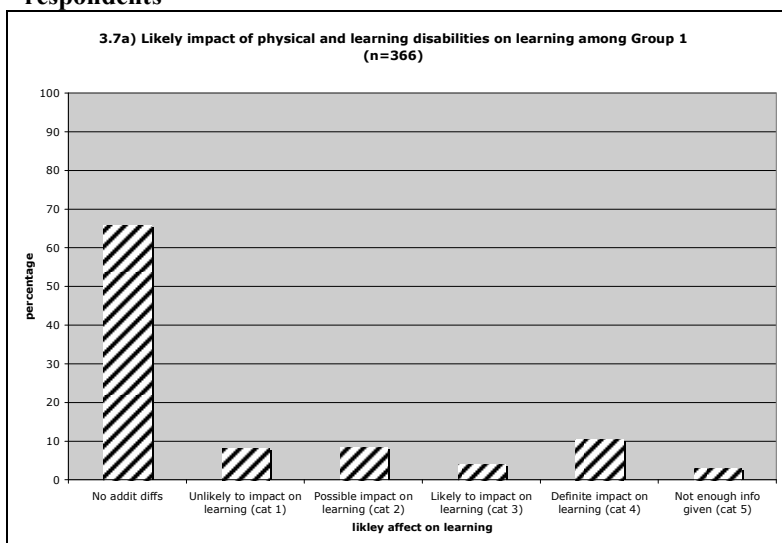
| Category | Description of construct | Examples |
|------------|---|---|
| Category 1 | Unlikely to impact on learning (but not categorical, due to possible affect on school absence) | Diabetes; asthma; arthritis; respiratory conditions; eczema; 'wears glasses' |
| Category 2 | Possible impact on learning; insufficient detail to know for sure | Cerebral palsy (possible impact, though not always clear from response); behavioural difficulties (where not formally diagnosed); |
| Category 3 | Likely to impact on learning (condition usually associated with learning difficulties and/or combination of category 1 and category 2 conditions) | Charge Syndrome |
| Category 4 | Definite impact on learning | Down's Syndrome; global delay; formal diagnosis as visually impaired. |
| Category 5 | Not enough information given | 'rare syndrome affects growth and causes mobility problems' |

The same categories were used for the Family Survey. The visual impairment coding was undertaken by a qualified and experienced orthoptist. However it was not possible to obtain the services of a specialist paediatrician to code the remaining data. Therefore I coded the data myself, referring to the detailed notes of the paediatrician who had completed the pupil survey, as well as medical reference literature. This means that the resulting categorisation will be viewed with care during the analysis.

On the other hand, there were two advantages to the Family Survey data itself. Firstly, the reports came from parents, who could be expected to report medical details accurately more consistently than teachers (particularly compared to visiting teachers, who may not always have access to accurate medical information). Secondly, because most children also had pupil records, it was possible to cross-reference where information in the Family Survey response was not clear.

Chart 3.7 (a-c) shows that the profiles of Group 1 and Group 2 cases are reasonably similar, with slight differences between the 'possible' and 'likely' categories. This was unexpected, as it had been assumed that there might be higher levels of definite/likely categories among Group 2 cases. It had been conjectured that the presence of complex difficulties may have meant particular challenges for parents in teasing out the effects of hearing loss, and in arranging adequate specialist service provision and that, therefore this may have provided an explanation for parents going to the trouble of completing and returning questionnaires, where their child had only a very mild hearing loss.

Chart 3.7 Likely impact on learning of physical and learning difficulties among deaf children of respondents



ADPS pupil survey data was coded in this way in 2000/01 only, so this has been used for comparison (chart 3.8). Fortnum et al.'s 1998 MRC UK-wide study (Fortnum et al., 2002) published the proportion of all disabilities, difficulties and conditions reported by respondents, from both health and education sources. In order to compare Family Survey, pupil survey and the MRC study, chart 3.8 provides information on all categories of reported data on 'additional difficulties'. The chart also shows what happens to the pupil survey and Family Survey results when Category 1 reports ('unlikely to impact on learning') are assumed to indicate no impact on learning.

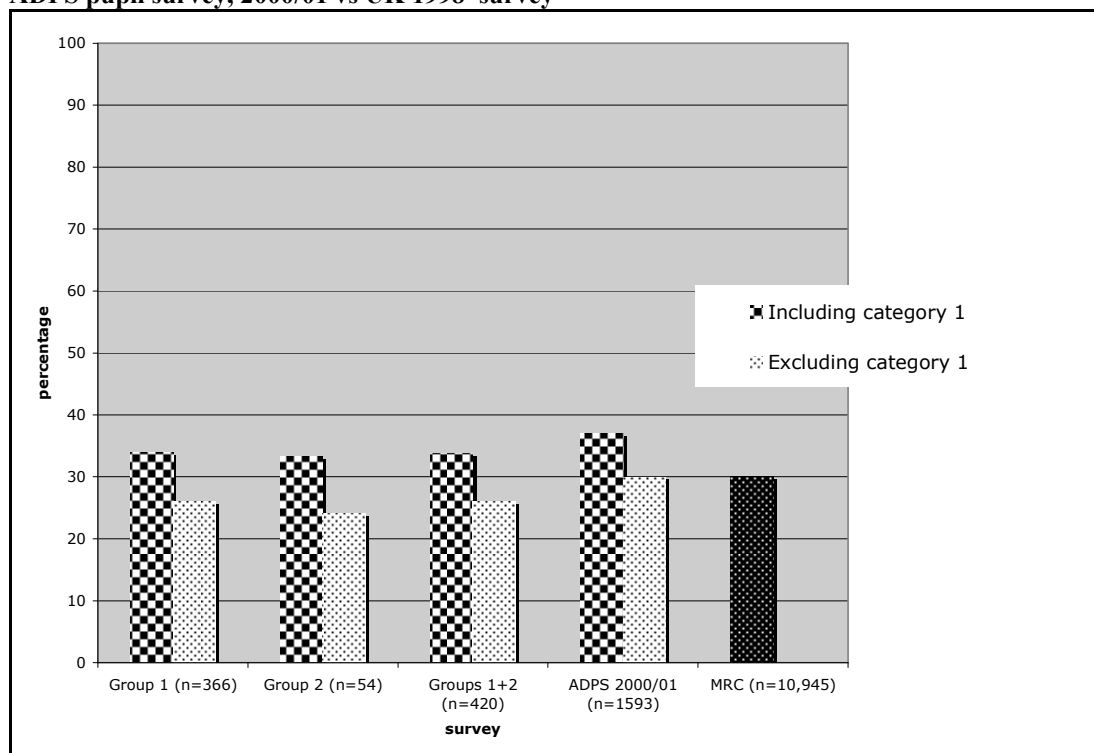
It can be seen that the proportion of Family Survey respondents' children with any type of report of 'additional difficulty' is slightly higher than that reported by the MRC's detailed 1998 UK study (Fortnum et al., 2002). However, the equivalent ADPS data shows a higher figure of 37%. It may be that the involvement of health professionals in the MRC study meant that incidences of 'category 1'-type conditions were disregarded, thus explaining the almost exact match between the ADPS 'excluding category 1' proportion and the MRC percentage.

When category 1 'unlikely' cases are excluded from both Family Survey and pupils survey results, then the percentage with learning-related difficulties drops in both Family Survey and ADPS populations, bringing the proportions closer together in comparability. Statistically, the learning-related difficulties/no learning-related difficulties profile of Group 1+2 is the only one of the three Family Survey populations to be significantly different from that of ADPS. Again, there may be some distorting effect from the fact that different categories of respondents (ie parents versus teachers) completed the two surveys, and also because of potential differences in judgements made by respective ADPS and Family Survey coders - despite best efforts to be consistent.

Therefore, although it seems that children and young people with physical and learning difficulties may be slightly under-represented in the Family Survey

sample, this needs to be treated with some degree of caution in analysis. It is suggested that there is a case for further research work in this area, in order to create an agreed means of categorising ‘additional difficulties’ most meaningfully, so that comparisons can more robustly be made between different studies of deaf children and between populations of deaf and hearing children.

Chart 3.8 Incidence of visual impairment, physical and learning difficulties: Family Survey vs ADPS pupil survey, 2000/01 vs UK 1998 survey*

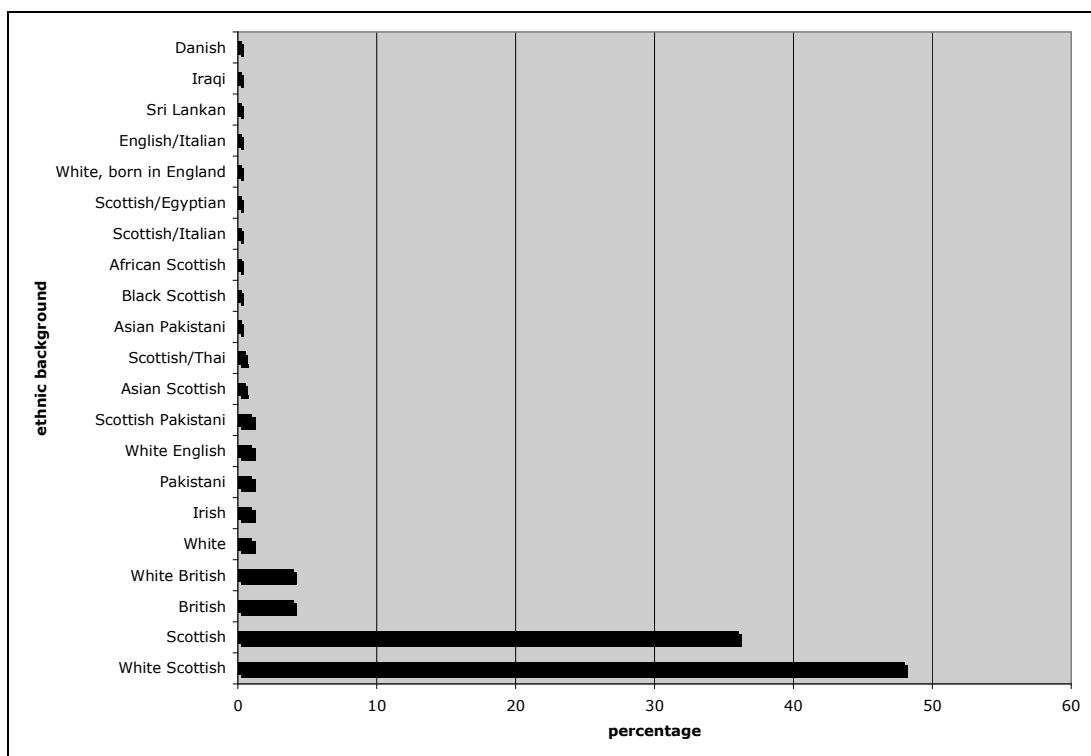


*(Fortnum et al., 2002:137)

Ethnic background

As detailed in the previous chapter, respondents were asked to describe the ethnic background of their deaf child by completing an open question, so that resulting data reflected constructs of ethnicity which were most meaningful to respondents. The results were initially coded only where responses were very similar (eg where the same words were spelt slightly differently). Chart 3.9 shows this detailed breakdown.

Chart 3.9 Ethnic background of deaf children of respondents (n=408*)

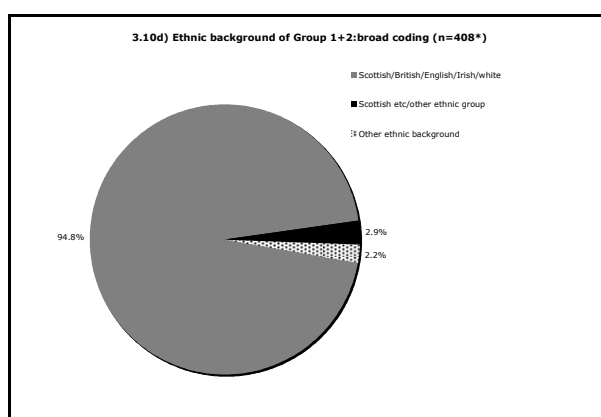
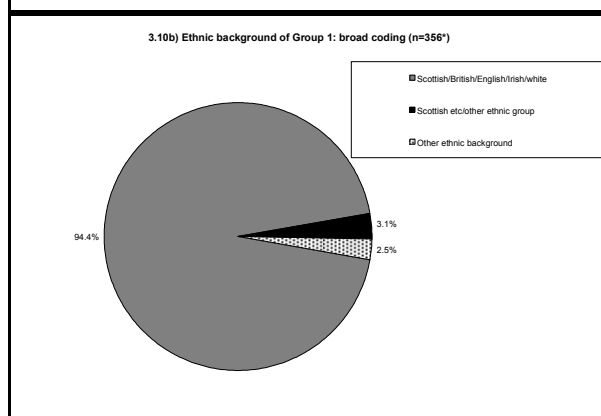
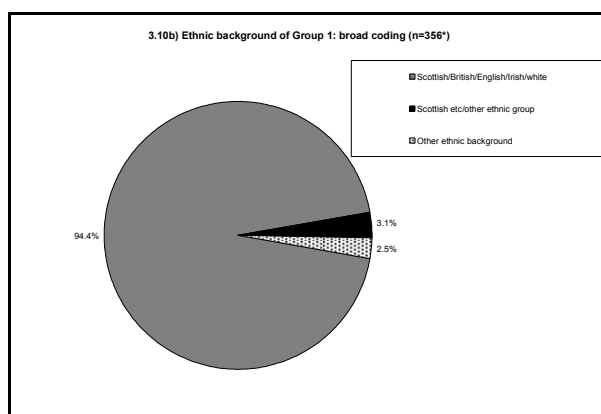
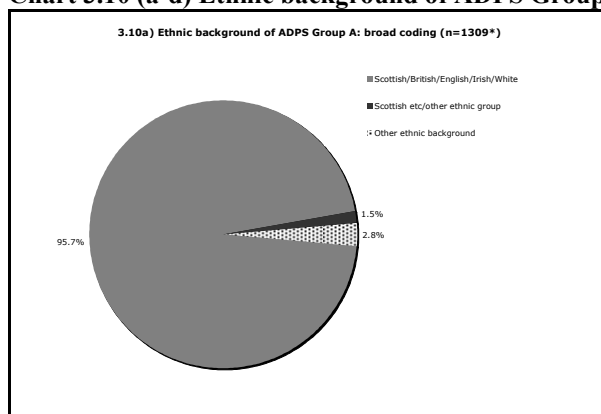


*total no. cases where relevant information was provided

When the categories are collapsed, in order to provide comparison with the ADPS population, the vast majority of deaf children are shown to have an ethnic background which is solely rooted within the British Isles; six children described simply as ‘white’ have been included in this group (Charts 3.10 [a-d]). The remainder have other ethnic backgrounds, either solely or combined with British Isles/white.

The proportions in the ADPS sample are too small for reliable comparison with Groups 1 and 2, using the chi-squared test. However, the percentage of ‘other ethnic groups’ in Group 1+2 (2.2%) is close to that in the ADPS population (2.8%), while the percentage of ‘Scottish/other ethnic groups’ (2.9%) is somewhat higher than in the ADPSD population (1.5%). The numbers are too small for this latter difference to be likely to affect the findings in any substantial way.

Chart 3.10 (a-d) Ethnic background of ADPS Group A and of deaf children of respondents



*total no. of cases where information was provided

Main language(s) used at home

General issues

As noted in chapter 1, language development is a particularly significant issue for deaf children. In order to produce as nuanced a report as possible, parents were asked to describe details about language use within the family via open questions, stating all languages where more than one was used. Aggregate categories were constructed by coding responses. Data on main language(s) used at home within the family is reported in this chapter, as a contribution to the demographic profile of respondents. Other information on language use will be reported in chapter 4.

Respondents were asked to state the main language used at home within the family, and, where two languages were used equally, to detail them both. Some respondents volunteered information that spoken English was supplemented with signs in some form (eg ‘Sign Supported English’, ‘Signed English’, ‘limited signs’ or ‘Makaton’). As respondents were not specifically asked to detail the extent of usage of manually coded English, it is not possible to know how many others may have supplemented English with signs, in one way or another. It should therefore be noted that these instances have been included as ‘English’ here, rather than separately categorised as differing mode(s) of English.

The ADPS pupil survey asked teacher respondents to indicate the main language(s) used in the deaf child’s home, and so chart 3.11 sets out this data for 2003/04, alongside Family Survey data. Given the importance of the language data, relevant charts and tables provide detailed keys to language categories. A relatively high proportion of teacher respondents (14%) did not complete information about main language(s) used at home, and a further 2% indicated ‘not known’. This contrasts sharply with the Family Survey, where only 2% of respondents did not provide information, and undoubtedly relates to the fact that teachers are, effectively, ‘third parties’ in completing details about a child’s home situation. It should be said that, because the ADPS pupil survey used third party reports, it is not guaranteed to

be as fully accurate a picture as that which would have been gained directly from families themselves, and should thus be treated with some reservation.

Bearing all this in mind, chart 3.11 shows that the main language was English in the vast majority of both survey populations, with the pupil survey having the highest proportion (89% versus 83%). Although the proportions of other language categories were relatively small, there were some differences between the Family Survey and the pupil survey population profile. In particular, larger proportions of Family Survey respondents reported bilingual (or multilingual) situations, the biggest differential relating to BSL/English situations (14% [Group 1] and 12% [Groups 1+2] vs 7% [pupil survey]).

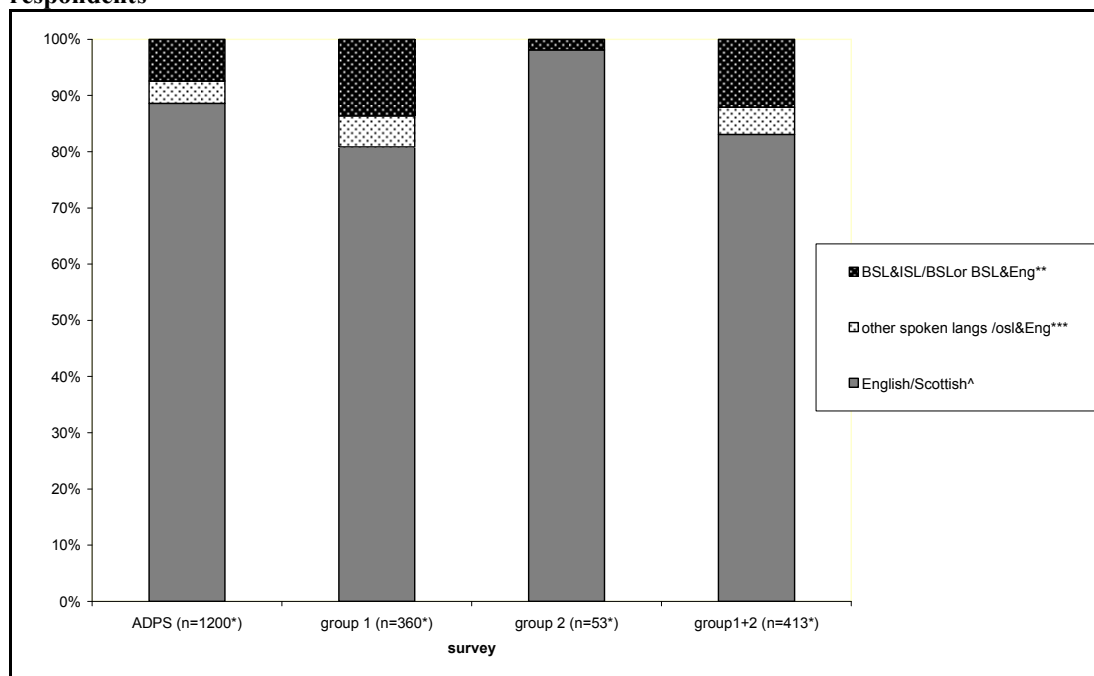
A methodology-related reservation should be noted in relation to reports of multi-lingual and bilingual situations. Both survey populations were asked to indicate more than one main language, where this was relevant. However the instruction was more explicitly given to Family Survey respondents, who were also invited to complete an additional option of 'other languages used at home'. Had this 'other language(s)' data been included as 'main language(s)', 19 monolingual cases would have presented as bilingual or multilingual. Therefore, it may be that some of the differences between the two sets of responses are relatively arbitrary, in terms of extent of usage of more than one language in the home, and some caution is needed in making direct comparisons. In data analysis, whether or not languages other than English were reported as being used bilingually with English, they have been considered as single categories ('BSL/BSL English' and 'other spoken language[s]/other spoken language[s] with English').

Analysis

The vast majority of the Family Survey and ADPS pupil survey families use English as the main language at home. The Group 2 distribution numbers are too small for chi-squared testing. While the distribution patterns of the Family Survey total population (Groups 1+2), and of Group 1, have a similar pattern, they are both significantly different from the ADPS population. This is due to the slightly higher

proportions of Family Survey families who reported that they used BSL as a main language. This will need to be borne in mind when reporting findings in chapter 4.

Chart 3.11 Main language(s) used at home of ADPS Group A, 2003, and of deaf children of respondents



* total no.of cases where relevant information was provided

** ISL = Irish Sign Language

*** Urdu; Urdu/Punjabi; Bengali; Arabic; Gaelic.

English/Gaelic; English/Doric (Doric has been classed here as a language rather than as a dialect); English/Punjabi; English/Danish; English/Urdu; English/German; English/Malagasy; English/Thai; English/Hindi; English/Tamil; English/Arabic; English/Spanish; English/Turkish; English/Japanese; English/Swedish.

^The exact term 'Scottish' (as distinct from 'Scots') was used by 2 Family Survey respondents.

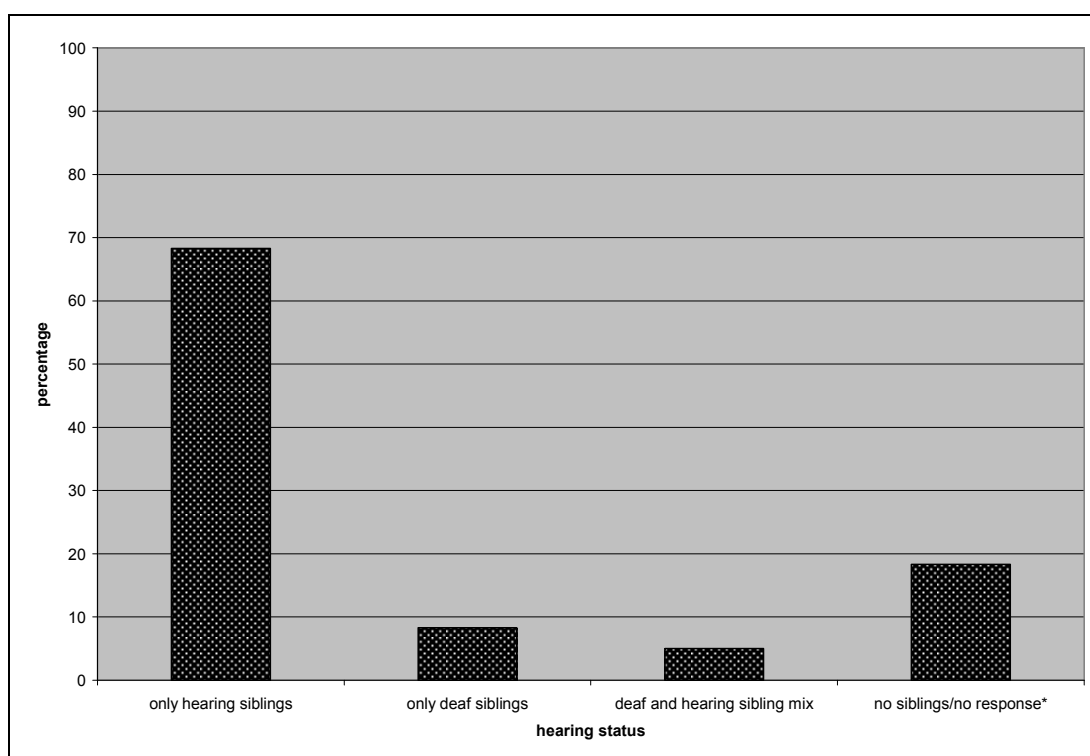
The Family Survey data is inevitably richer than the pupil survey in terms of linguistic information about families, as more detail was requested, and as the families themselves were informants. Some of this will be explored in chapter 4, but it is perhaps worth noting, at this point, that the data highlights the linguistic complexity of the environment for some deaf children in Scotland, with nineteen percent of the total number of deaf children of respondents (79) living in a home where two or more languages were used. The ADPS pupil survey data includes one situation where BSL plus two spoken languages other than English were used within the family.

Hearing status of siblings

Thirteen percent of deaf children of respondents were reported as having at least one deaf sibling. The vast majority (68%) had hearing siblings and no deaf siblings (chart 3.12).

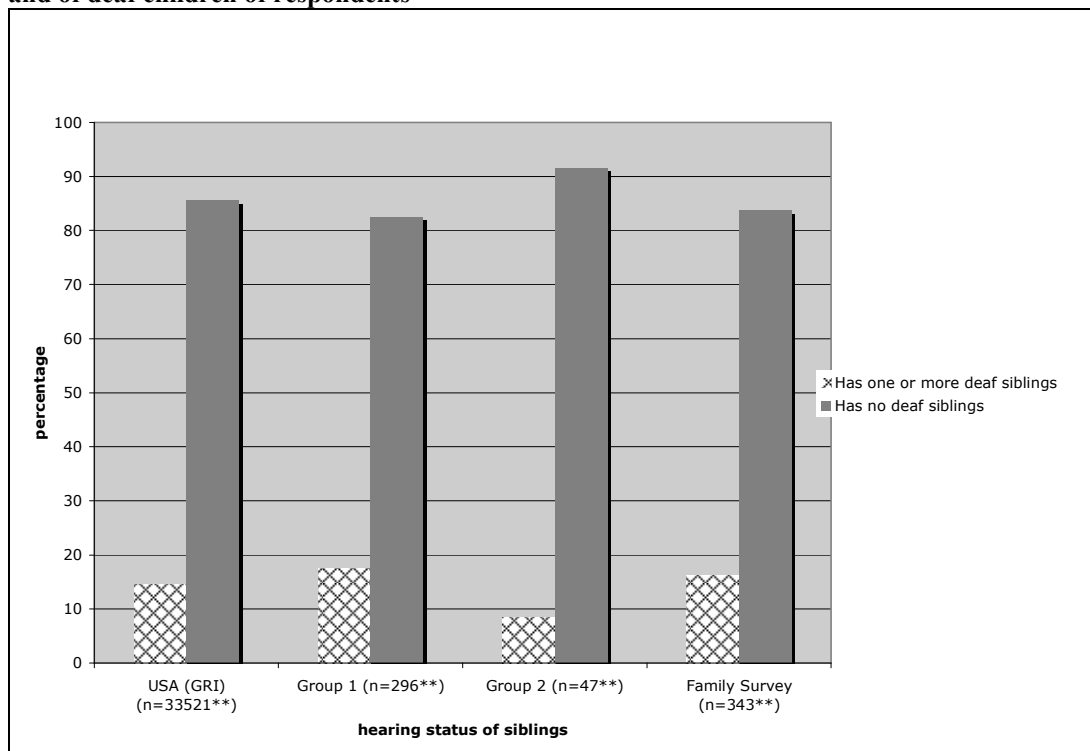
The Gallaudet Research Institute (GRI) collects annual information on deaf children across the USA, and includes information on sibling hearing status. It should be borne in mind that the GRI population only covers around two thirds of potential population and is most likely to be skewed towards those in specialist provision (such as units and special schools). Therefore, although the overall population numbers are comparatively large, there is a chance that families with deaf siblings may be slightly over-represented. Bearing this in mind, Chart 3.13 shows that the proportion of deaf children with deaf siblings in the total Family Survey population (Groups 1+2), and in Group 1, are very similar to (and, statistically, not significantly different from) that among the GRI population.

Chart 3.12 Hearing status of siblings of deaf children of respondents (n=420)



*respondents were clearly asked for hearing status and ages of all children in separate questions. However, as there was not a specific yes/no question ascertaining whether the deaf child was the only child, it is just feasible that some of this group did have siblings.

Chart 3.13 Hearing status of siblings of USA (Gallaudet Research Institute) population 2003/04* and of deaf children of respondents



* (Gallaudet Research Institute, 2005)

** total no. cases where relevant information was provided

Determination of sample for analysis

Taking all the above comparisons into account, it is clear that, in most cases, the data for Group 2 has least correspondence with the relevant comparator population, and that the profile of this group is heavily skewed towards school-age children with slight hearing losses in mainstream school placements within a limited number of local authorities. Consequently there is a case for the 54 cases concerned to be excluded from analysis and it has been suggested that analysis of findings relating to this group could usefully be undertaken in further study.

By contrast, the profile of Group 1 has similarity with the comparator populations, in so far as no statistically significant difference was found in terms of: age; gender; ethnicity and hearing status of siblings. There was also a reasonable comparability in terms of geographical spread. However, the profile of Group 1 population of deaf children and young people was shown to be statistically skewed

towards: those of preschool age; those who had a severe hearing loss or cochlear implant; those where BSL was reported as a main language at home, and those in mainstream school placements.

Therefore, while it seems that Group 1 population is the most appropriate sample to use for analysis of findings, the various skews in profile will need to be taken into account where relevant. Also, as detailed above, caution will need to be advised when drawing conclusions based on constructed variables relating to learning difficulties and to main languages used at home.

The next section will explore the extent to which the parent respondents can be seen as representative of the general parent population in Scotland, both socio-economically and in terms of hearing status.

Demographic profile of parents

Family Survey data relating to socio-economic status of families comprised: family income; highest educational level of parents, economic activity of parents and parental occupation. The potentially most suitable comparator population was that identified by the Scottish Household Survey (SHS). Unfortunately, it proved impossible to obtain SHS statistical information which was sufficiently harmonious with the Family Survey data.

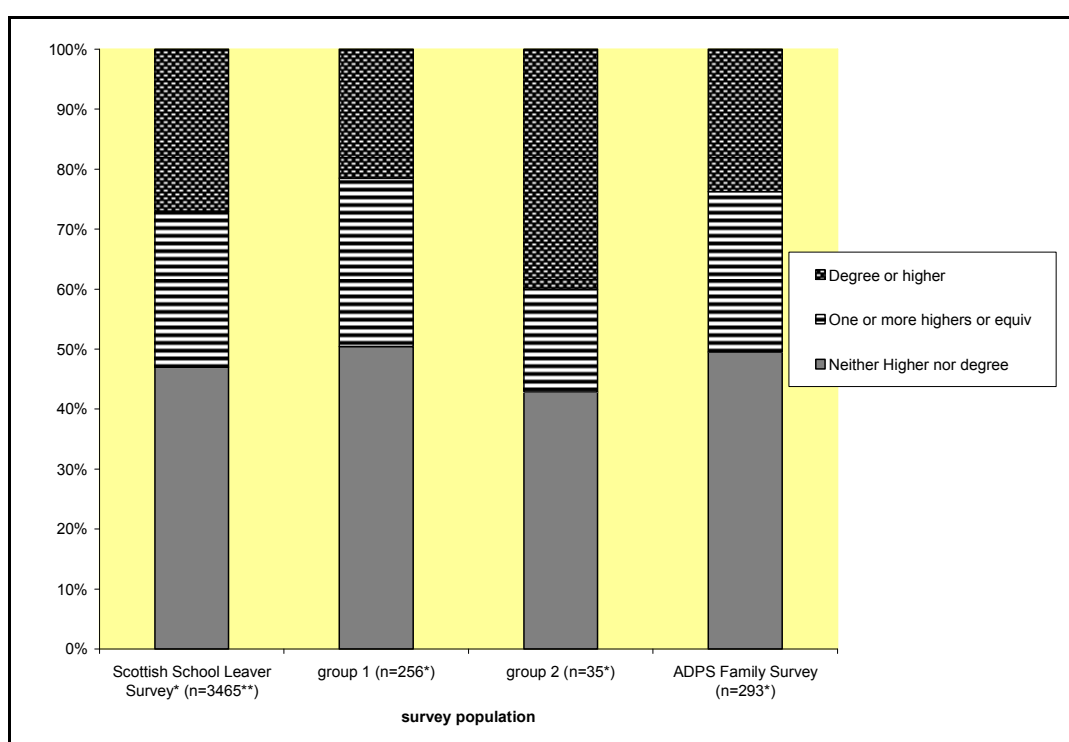
However, in 2003, the Scottish School Leavers Survey (SSLS) collected socio-economic data, via self-completion questionnaire, from 5088 young people in Scotland who were around 16 years old. Bandings relating to family income were not coterminous with Family Survey bands, and therefore income data has been disregarded here. However, data relating to highest level of qualification and employment of parents was harmonious and has therefore been used for comparison. It should be taken into account that, although there has been shown to be a slight skew towards preschool-age children in the Family survey population, there are

likely to be some differences between the populations – particularly in view of the fact that the SSLS parental population was probably older and less likely to have very young children at home.

Highest educational qualifications of parents

The SLSS categories were collapsed from seven to three in the 2003 sweep report, and, therefore, the Family Survey categories were similarly collapsed, so that direct comparison is possible. Charts 3.14 and 3.15 show that the profiles of the Family Survey data are very similar for both mothers and fathers. The only minor difference is that a slightly higher proportion of Family Survey mothers have a maximum qualification level of at least one Higher or equivalent, and slightly lower proportions in both lower and higher level accreditation. Statistically, however, there was no significant difference between the distributions of Group 1 or Group 1+2 populations and that of the SSLS.

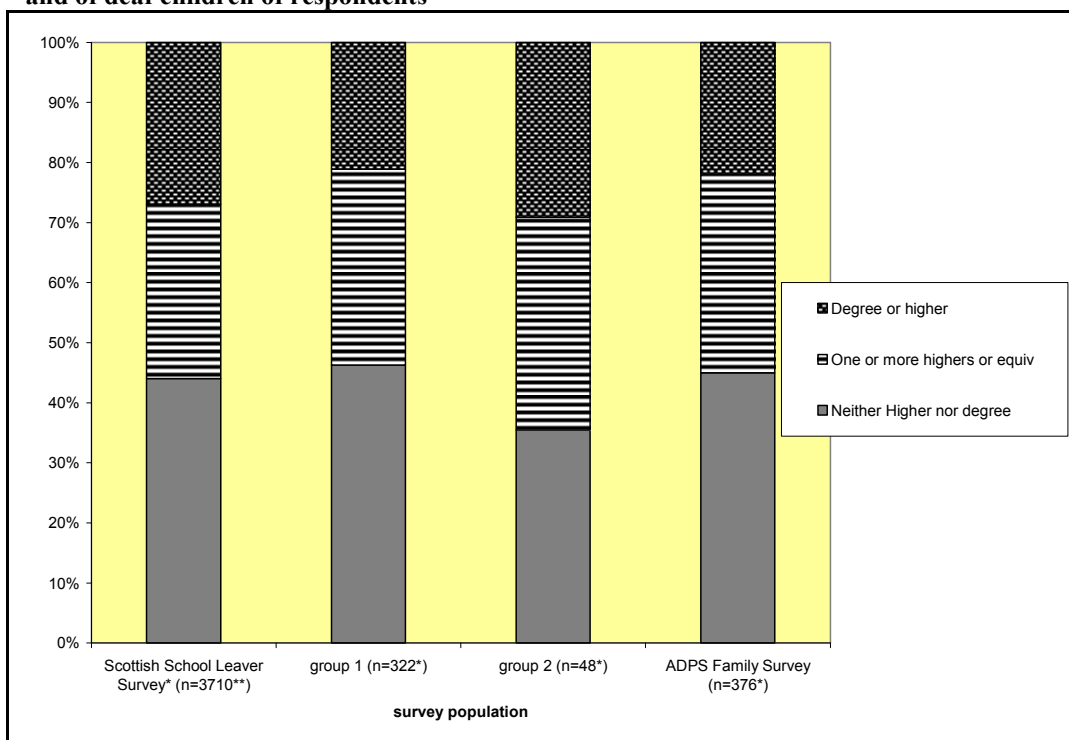
Chart 3.14 Highest qualification of fathers of Scottish School Leaver Survey population, 2003, and of deaf children of respondents



* total no. cases where relevant information was provided

** unpublished data

Chart 3.15 Highest qualification of mothers of Scottish School Leaver Survey population, 2003, and of deaf children of respondents



* total no. cases where relevant information was provided

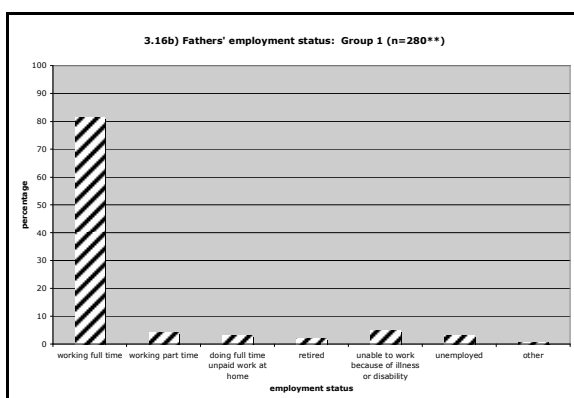
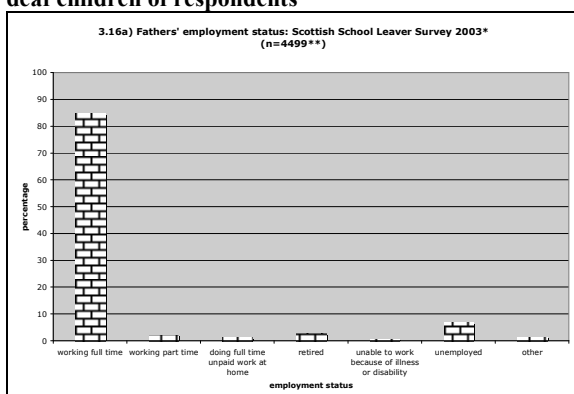
* *unpublished data

As already indicated, the SSLS data relates to parents of upper secondary age pupils, whereas the age group of children of Family Survey respondents also included those of lower secondary, primary and preschool levels. Implications of this will particularly be taken into account in relation to parental employment-related data.

Economic activity of parents

Charts 3.16 and 3.17 illustrate the extent to which parents are in paid employment. The Family Survey profiles for fathers (total group and the two sub-groups) look relatively similar to that of fathers in the SLSS: the vast majority of fathers in all groups were in full-time work with some minor differences among other categories of economic activity (chart 3.16 [a-d]). However, when these latter categories are amalgamated, Group 1+2 and Group1 both show significant statistical difference due to the lower proportions of fathers in full-time work.

Chart 3.16 (a-d) : Employment status of fathers of Scottish School Leaver Survey Population, 2003, and of deaf children of respondents



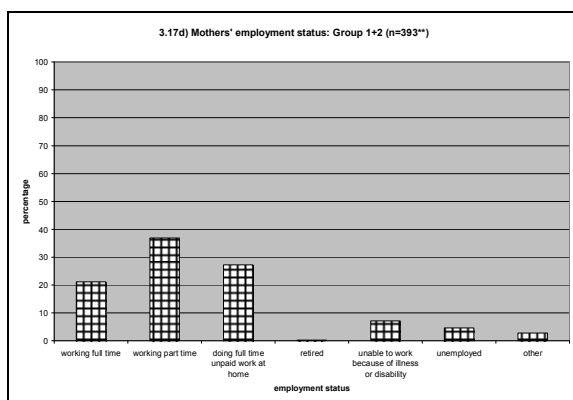
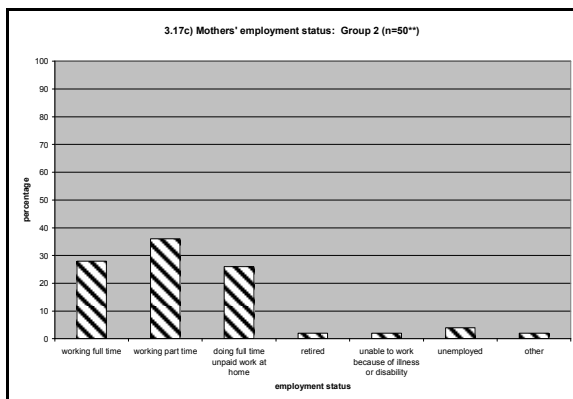
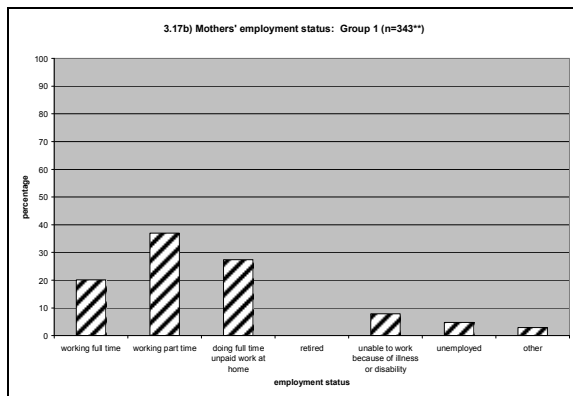
* unpublished data

** total no. cases where relevant information was provided

In the case of mothers (chart 3.17 [a-d]), there is a highly significant difference between the Family Survey profiles and that of SSLS. Among the Family Survey population, less than half the proportion of mothers worked full time as did those in the SSLS group (21% vs 52%), and more of them worked part-time or were doing full time unpaid work at home. In fact, more than twice as many Group 1 (and Group 1&2) mothers were doing unpaid work at home.

As the SSLS data relates to parents of upper secondary school pupils, the Family Survey data used in additional charts 3.18 and 3.19 relates only to parents of secondary level pupils (Group 1), in order to reduce the potential confounding effect which the inclusion of parents with younger, more dependent children may have. However, these second two charts show a similar pattern with a statistically significant skew away from full-time work among fathers and a highly significant difference between the two populations of mothers: again, a lower percentage of mothers was in full-time work and a higher percentage was doing unpaid work at home. It is conceivable that this may be related to findings within the literature cited in chapter 1, which indicate that mothers tend to spend more time than fathers concentrating on the language and communication development of their deaf child: Eriks-Brophy et al. (2007); Gregory et al. (1995) and Skelton & Valentine (2002). However, it is conceivable that the skew away from full-time work among respondent fathers may indicate a development in traditional gender roles: a possible increased likelihood of fathers spending more time with their deaf child at home. It would be necessary to explore this situation through further in-depth study before drawing any conclusions.

Chart 3.17 (a-d): Employment status of mothers of SSLS Population, 2003*, and of deaf children of respondents



* Scottish School Leaver Survey unpublished data

** total no. cases where relevant information was provided

Chart 3.18: Employment status of fathers of SSLS pupils*, 2003 (n=4499) and of fathers of Group 1 secondary level pupils (n=111**)**

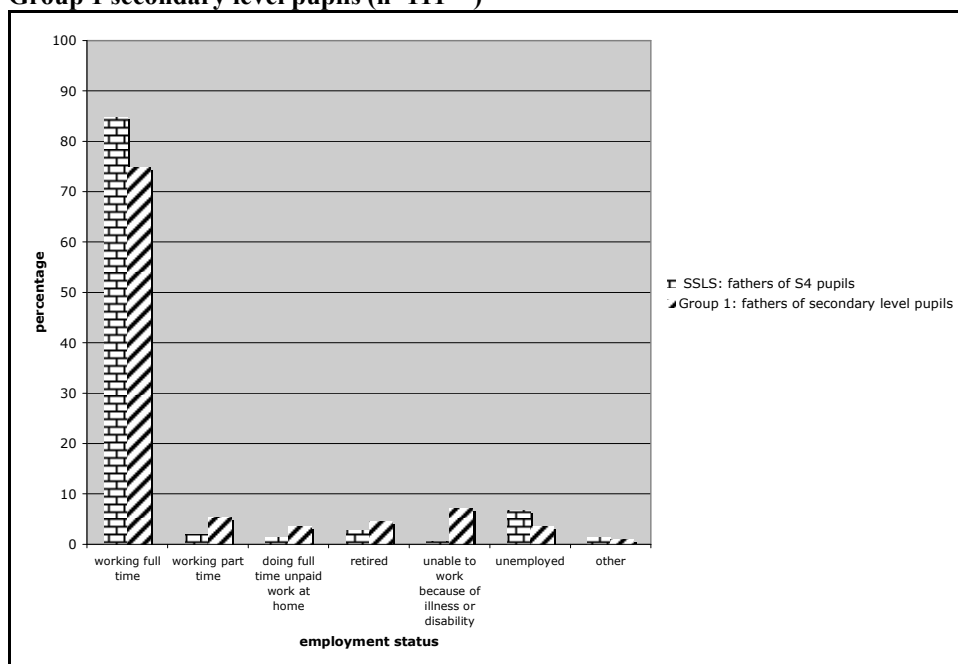
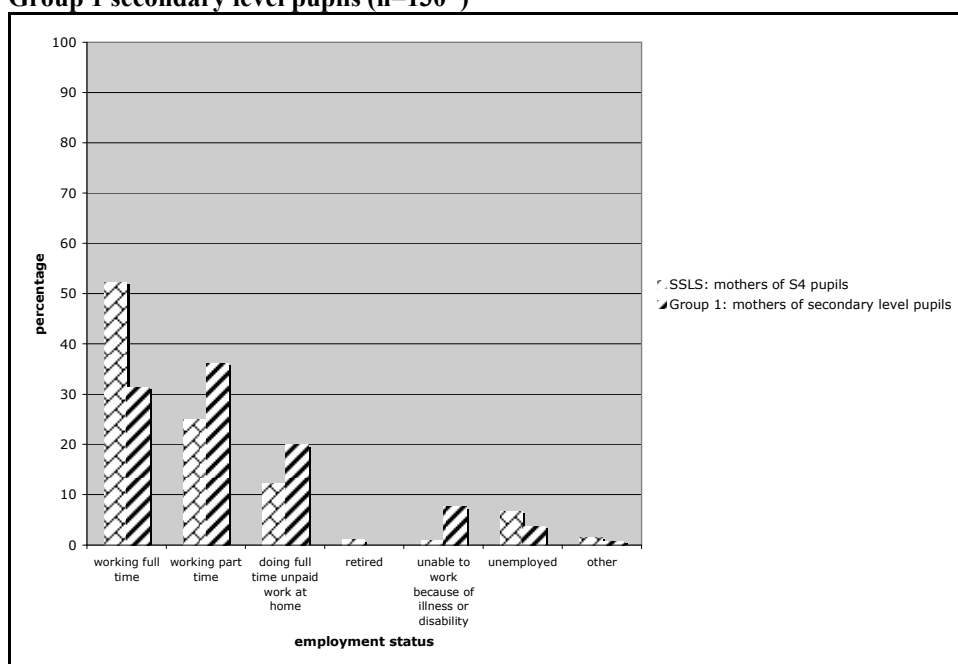


Chart 3.19: Employment status of mothers of SSLS pupils*, 2003 (n=4844), and of mothers of Group 1 secondary level pupils (n=130*)**



* Scottish School Leaver Survey unpublished data

** total no. cases where relevant information was provided

Parental occupational classification

Each parental job title reported by respondents was individually assigned to one of the nine Standard Occupational Categories used by the Office of National Statistics (Office for National Statistics, 2000). In order to compare with the SSLS data, the categories were collapsed into three social class bands, with a fourth ‘unclassified’ band covering all situations where insufficient information had been given to enable classification of paid employment. Resulting data show that there are statistically different profiles for fathers and for mothers within Family Survey respondents households, compared to respective parent groups in SSLS households (charts 3.20 and 3.21). However, chart 3.22 demonstrates that, when the highest SOC band between the father and mother in each household is used, the overall pattern of household social class banding between SSLS and Family Survey respondents is more similar than that for either parent group, with Group 1 distribution being nearest. There still remains a statistically significant difference, due to the skew towards a higher social class level within the population of Family Survey households, and this will need to be borne in mind when reporting relevant findings.

As the percentage of ‘unclassified’ is higher for the Family Survey households, the detail of this was further investigated. The exploration showed that, within these families, the ‘unclassified’ banding among the mothers tended to relate to them doing unpaid work at home or being unemployed; whereas that for the fathers was most likely to relate to no response have been provided. The mothers’ situation may, again, possibly reflect a greater tendency to remain at home because of factors relating to their deaf child.

Chart 3.20 Fathers' Standard Occupational Classification: SSLS*, 2003 vs Family Survey

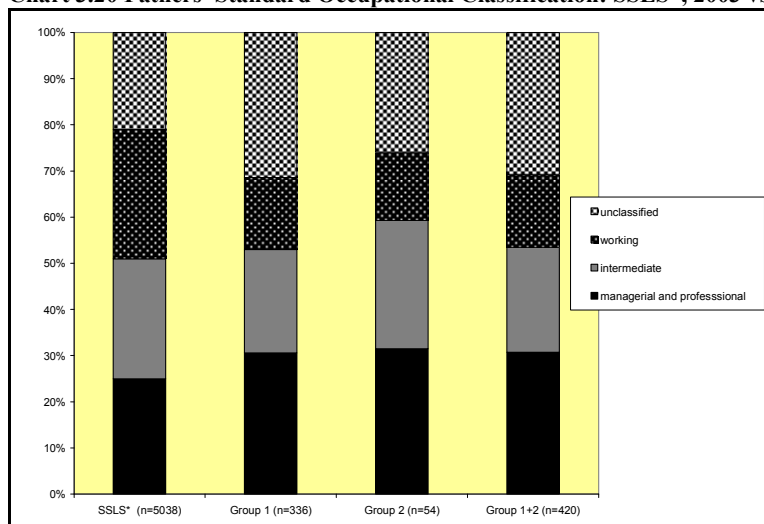


Chart 3.21 Mothers' Standard Occupational Classification: SSLS*, 2003 vs Family Survey

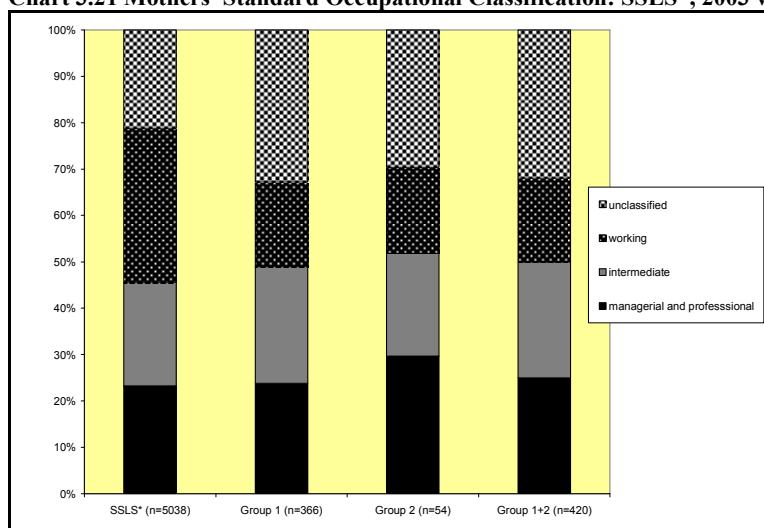
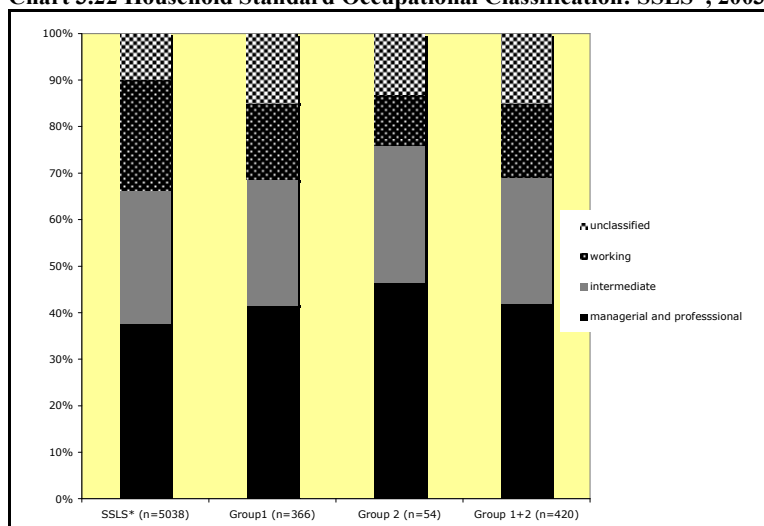


Chart 3.22 Household Standard Occupational Classification: SSLS*, 2003 vs Family Survey



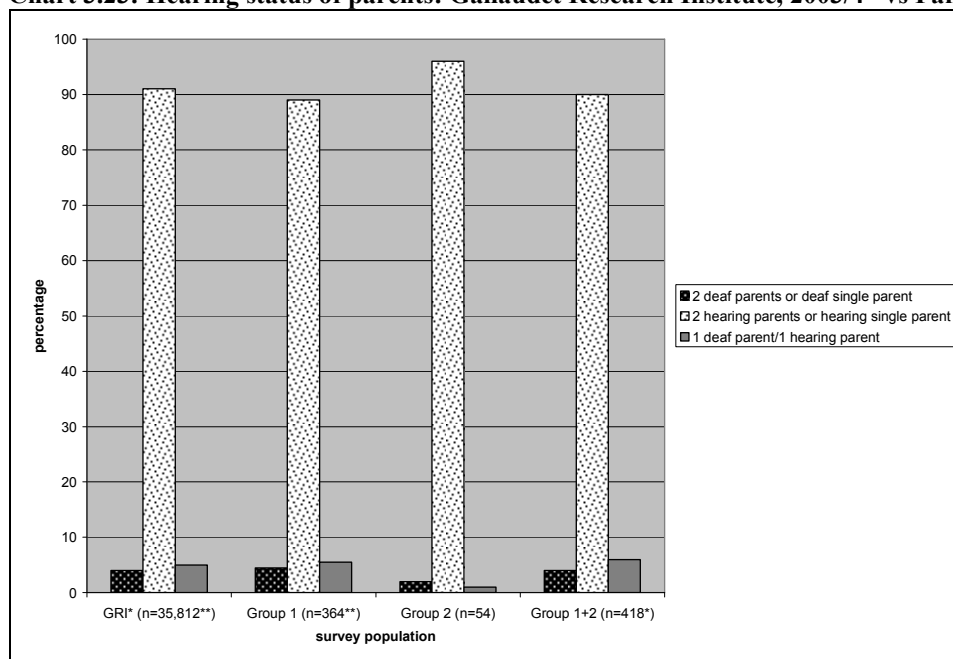
*Scottish School Leaver Survey (unpublished data)

Therefore, taking into account all socio-economic information relating to household income and to qualifications and occupation of parents, it can be seen that the profile of the Family Survey population has similarities with the socio-economic profile of parents of upper secondary stage Scottish pupils. The main differences are: a skew towards higher social class, as defined by occupational status; in terms of fathers' employment status, a skew away from full-time work; and, in terms of mothers' employment status, a highly significant skew away from full-time work and towards unpaid work at home. While all of these differences will need to be borne in mind, whenever relevant, during analysis, the skew towards higher household occupational status will be an issue whenever socio-economic issues are explored, as this variable will be used as a proxy measure of socio-economic status.

Hearing status of parents

The literature review pointed towards differences in experiences of deaf children with deaf parents compared to those with hearing parents. Therefore is pertinent to identify the representativeness of the Family Survey population in terms of hearing status of parents. As with hearing status of siblings, Gallaudet Research Institute (GRI) is the main comparator population, and the same proviso about population skew towards children in more specialised school placements – raising the possibility of over-representation of deaf parents. Bearing this in mind, Chart 3.23 shows that the proportion of deaf parents in the Family Survey is very similar to that among the 35,812 parents in the GRI population whose parental hearing status is known. As might be expected, statistical testing showed up no significant difference between profile of either Groups 1+2 or Group 1 and the GRI population.

Chart 3.23: Hearing status of parents: Gallaudet Research Institute, 2003/4* vs Family Survey



* source: (Gallaudet Research Institute, 2005)

**total no. cases where relevant information was provided

In summary, therefore, the profile of Group 2 children and young people has been shown to be very different from that of comparator populations. It has been suggested that, while there are arguments for future exploration of Group 2 data, the analysis of findings for this thesis should therefore focus on the 366 cases in Group 1; nothing in the exploration of parent demographic profiles contra-indicates this suggestion.

While it has been demonstrated that the Group 1 population is representative of the comparator populations in terms of age, gender, ethnicity and in the hearing status of siblings, there are a number of profile skews which will need to be borne in mind when reporting findings. In particular, this group were more likely to:

- be of pre-school age;
- have a cochlear implant or a severe hearing loss (compared to other hearing loss level bandings);
- be in mainstream school placement;
- live in a home where BSL was used as a main language.

It was also shown that respondent parents were representative of the nearest comparator populations in terms of highest educational qualification and hearing status. Again there are some parent profile skews to take into account during data analysis. Firstly, households were more likely to be of higher social class, in terms of highest parental occupational classification. Of most striking difference is the economic activity profile of mothers, whose relatively high likelihood of being at home rather than at work seems to correspond to substantive literature indicating that hearing mothers with deaf children tend to take on a significant didactic role which involves additional time at home. It has been conjectured that the skew in the economic profile of fathers away from full-time work may suggest a gender development relating to this parental role, which would be worth exploring in future research.

An addition to these restrictions to sample representativeness, benefits of, and limitations to, the application of key constructed variables (learning difficulties; main languages used at home) have been described - in terms of using them within a context of caution.

Bearing all of this in mind, the following two chapters concentrate on analysis of findings. Chapter 4 focuses on language and communication in the family and chapter 5 explores data relating to friendships, participation in activities and parental challenges in nurturing their deaf adolescent children's independence.

Chapter Four: Findings Relating to Deaf Children's Language and Communication in the Family

In the previous chapter, basic demographic information about respondents and their deaf children was described, including data on main language(s) used at home within the family. The majority of this chapter is devoted to the application of Group 1 survey data to the first research question, which focuses on the quality of communication between deaf children and family members; data is presented in the context of the substantive literature reviewed in chapter 1. Before beginning this presentation of findings, the chapter begins by detailing more specific information on the first language(s) of the deaf children of respondents, factoring in more specific information about languages used with individual members of the family to enrich detail of individual cases.

First language(s) of Group 1 deaf children of respondents

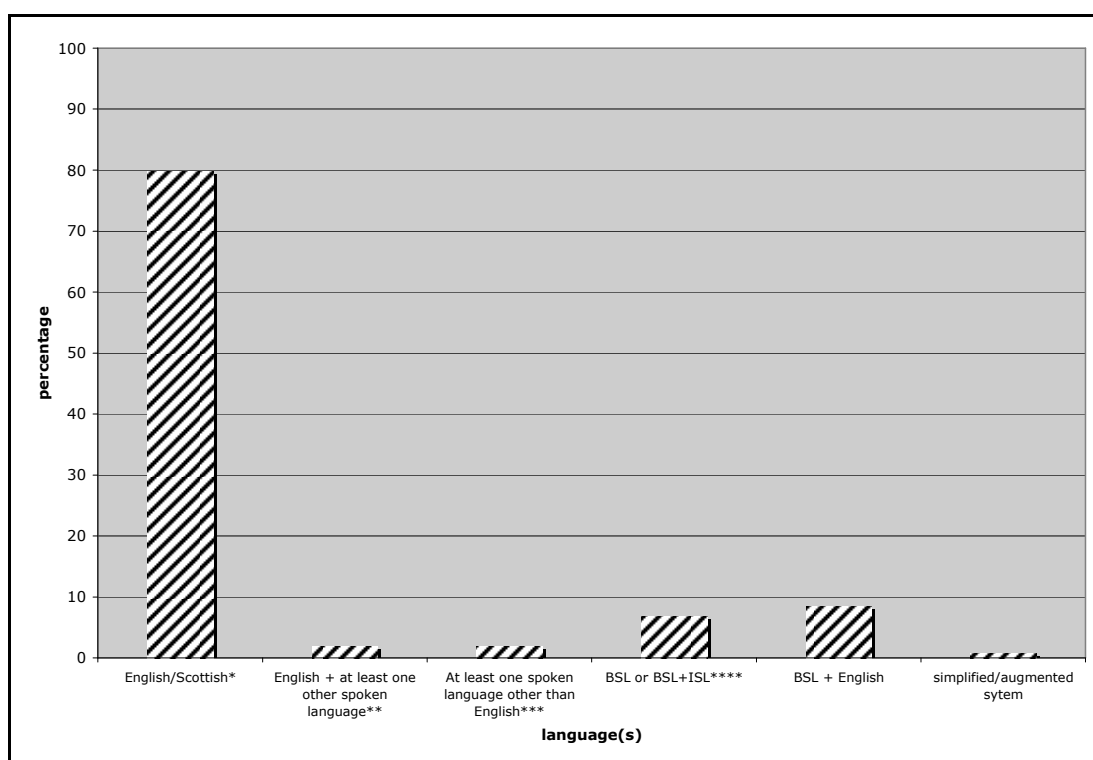
As already emphasised, language development is a particularly significant issue for deaf children. Parents were asked to describe their deaf child's first language, and other information about language(s) used at home, via open questions, stating all languages where more than one was used. Aggregate categories were constructed by coding responses and, given the importance of the language data, relevant charts provide detailed keys to the category constructions.

As with 'language used at home' described in the previous chapter, some responses to the 'deaf child's first language' question volunteered information that spoken English was supplemented with signs in some form (eg 'Sign Supported English', 'Signed English', or 'limited signs'). For the reasons detailed in chapter 3, these instances have been included as 'English' in this sub-section, rather than separately categorised as mode(s) of English. However, where examples of simplified/augmented systems were reported (such as Makaton or Picture Exchange

Communication System [PECS]), these have been classified separately in this chapter, as normally indicating the existence of specific learning difficulty.

Chart 4.1 shows that the vast majority (80%) of Group 1 deaf children of respondents were reported to have English as their first language; a further 4% were reported as having at least one spoken language other than English, half of these in addition to English, and another 8.5% as having English plus BSL. Fifteen percent were reported as having a sign language as a first language, either monolingually or bilingually.

Chart 4.1: First language(s) of Group 1 children and young people (n=363[^])



* The exact term 'Scottish' (as distinct from 'Scots') was used by 5 respondents.

** English/Punjabi; English/Danish; English/Arabic; English/Urdu

*** Gaelic; Urdu; Tamil; Hindi; Urdu/Punjabi

**** ISL = Irish Sign Language

[^] total excludes 3 'no responses'

When hearing loss is factored into this situation, it can be seen that the vast majority of those with slight and moderate losses had English as first language (table 4.1). Only six children out of both of these hearing loss categories (cumulatively 3.5%) had BSL as well as English. Further data exploration revealed factors likely to

have been significant in these individual situations: two had deaf parents; three had definite/possible learning difficulties and one had a hearing loss profile which calculated as ‘moderate’, but which indicates a likelihood that speech sounds would be particularly challenging for the child to discriminate (profound loss in one ear and a high frequency skew to the hearing loss in the other ear).

Therefore, as might be predicted, the number and proportion of children reported as having BSL, or BSL and English, as first language(s) increases with the level of hearing loss: 16% (12) of severely deaf children and 44% (16) of the profoundly deaf children. As explained in the previous chapter, cochlear implanted children have been categorised separately because of the probable high impact of the implant on a profoundly/severely deaf child’s audition, while, at the same time, the implant being a ‘switch-offable’ device. While less implanted children than profoundly deaf children had BSL, or BSL and English, as first language(s), this number of implanted children represented twice the proportion of severely deaf children who had BSL as at least one of their first languages. Some implications of this will be explored later.

As with the main language(s) used at home, only a small number was reported as having one or more non-English spoken language(s) as first language(s): 7 monolingually and 7 bilingually (or multilingually) with English. As already noted, above, these 14 cases represent 4% of the Group 1 total, excluding the three ‘no responses’. As noted in chapter 1, it can be problematic where professionals encourage minority language-speaking parents to use only English with their deaf child. The Family Survey questionnaire did not ask the level of English spoken by parents. However, from the data on languages used with deaf child by individual family members, it did seem that some deaf children were using the minority language at home with parents and/or other family. This may indicate a policy and practice shift by professionals in Scotland, worthy of exploration in further study.

However, the linguistic complexities of some of these individual situations are notable. For example, in one family, an 8 year-old profoundly deaf child had two

first languages other than English (both spoken), but also used both English and BSL with different family members. In another, a 10-year-old moderately deaf child's first language, and home language, was a spoken language other than English; meanwhile, siblings also used English, and grandparents used yet another spoken language, with this child.

Table 4.1: First language of group 1 children by hearing loss level (n=363*)

| | not known | mild/unilat/ WNL ** | moderate | severe | profound | cochlear implant | Total |
|---|-----------|------------------------|----------|---------|----------|---------------------|-------|
| English/Scottish | 20(87%) | 64(100%) | 97(91%) | 59(78%) | 16(44%) | 34(60%) | 290 |
| Eng + at least one other sp lang | 0 | 0 | 1(0.9%) | 1(1%) | 3(8%) | 2(4%) | 7 |
| At least 1 sp lang other than Eng | 1(4%) | 0 | 3(3%) | 2(3%) | 1(3%) | 0 | 7 |
| BSL or BSL + ISL | 2(9%) | 0 | 0 | 5(7%) | 10(27%) | 8(14%) | 25 |
| BSL + Eng | 0 | 0 | 6(6%) | 7(9%) | 6(17%) | 12(21%) | 31 |
| Simplified/augme nted system | 0 | 0 | 0 | 2(3%) | 0 | 1(2%) | 3 |
| Total | 23 | 64 | 107 | 76 | 36 | 57 | 363 |

* total excludes 3 'no responses'

**within normal limits

Bearing this linguistic context in mind, the following sections in this chapter will address the main thesis research questions, again using 'Group 1' as the sample.

Research Question 1: Using parent reports, what is the quality of communication between deaf children and family members?

In this section, data from survey questions relating to communication between the deaf child and family members will be explored, in addition to any relevant information from open responses made in the final general question in the survey, which asked for 'any other comments' (see Appendix 3 for text of relevant questions).

Methodological issues

In section 2 question 1, respondents were asked to rate how well their deaf child communicated with individual members of the family. This question will be referred to, henceforth, as the ‘Quality of Communication Question’. It should be noted that the wording of the question suggests a ‘child to other person’ direction of communication. The decision was taken to word the question this way after some deliberation over the best way to elicit a sense of the child’s pro-activity in communicative situations. There was effectively a trade-off between the depth of data which would have been provided by asking separate questions about different communicative directions within 2-way communication and the need to limit questions, as described in chapter 2.

Responses were invited along a scale of 1 to 5. As discussed in chapter 2, it needs to be borne in mind that categories 2-4 were numerical only and were not labelled with text. Text labels have been constructed, as meaningfully as possible, for the purposes of reporting here (2=‘communicates quite well’; 3=‘communicates OK’; 4=‘does not communicate well at all’), but there is arguably a marginal degree of uncertainty that they will accurately reflect the intended meaning of the respondent.

Perhaps more seriously, it transpired, when analysing responses, that the designation of ‘communicates very well’ to the lowest value on the scale (1) and ‘does not communicate well at all’ to the highest (5), was counter-intuitive to some respondents. This was discovered when exploring unexpected patterns of parent responses; in particular, a surprisingly high number of ‘does not communicate well at all with mother’ responses related to children with a relatively small hearing loss and no reported learning difficulties: 14 relating to children with mild/moderate hearing loss compared to 6 relating to children with severe/profound loss. In most cases, perusal of the completed questionnaires revealed other information which confirmed that the scale had been applied in the opposite way to that intended. Typically,

comments had been written about languages used by, and communication between, individual family members, which indicated clearly that communication was good between deaf child and parent and, sometimes, clearly less good with other people.

Therefore, in order to be sure that this section of data was as robust as possible, each of the 420 questionnaires was scrutinised carefully to ensure that the response to this question was in harmony with other information provided in the questionnaire. In 46 cases there had clearly been an error, and the database was amended. The following two examples are characteristic:

Example 1

Although the mother respondent had completed the relevant question as shown in the middle column of table 4.2, she had added the comment, ‘more of a problem with people he does not know’; she had also indicated good communication between deaf child and parent in later specific questions about parent/deaf child conversations. Therefore, it was deduced that she had assumed that a higher number indicated a higher quality of communication and responses were amended to reflect her obvious intention, as shown in the right-hand column of the table.

Table 4.2: Amendments made in example 1

| | Quality of communication between deaf child and relative, as indicated in by respondent | Amended response |
|--|--|-------------------------------------|
| Mother | 5 (does not communicate well at all) | 1 (communicates very well) |
| Father | 3 (communicates OK*) | 3 (communicates OK*) |
| Brother and sisters | 3 (communicates OK*) | 3 (communicates OK*) |
| Other adults (eg uncle, grandparent) | 3 (communicates OK*) | 3 (communicates OK*) |
| Children/young people (eg cousin, niece) | 2 (communicates quite well*) | 4 (does not communicate that well*) |

* text label devised during the process of analysis

Example 2

Here the respondent had chosen the ‘does not communicate well at all’ option for all family members, but had later indicated that discussions between deaf child and parent were good - and had also stated specifically: ‘she manages very well with friends and family when communicating’. Table 4.3, below, shows how the response was amended, again to reflect obvious intention.

Table 4.3: amendments made in example 2

| | Quality of communication between deaf child and relative, as indicated in by respondent | Amended response |
|--|--|----------------------------|
| Mother | 5 (does not communicate well at all) | 1 (communicates very well) |
| Father | 5 (does not communicate well at all) | 1 (communicates very well) |
| Brother and sisters | 5 (does not communicate well at all) | 1 (communicates very well) |
| Other adults (eg uncle, grandparent) | 5 (does not communicate well at all) | 1 (communicates very well) |
| Children/young people (eg cousin, niece) | 5 (does not communicate well at all) | 1 (communicates very well) |

Many respondents had completed the scales the wrong way and then themselves had corrected the responses afterwards; in one case, a comment had been added to explicitly state that the responses had been changed due to assuming the highest value equated with highest level of communication.

There are three final notes of caution in relation to the objectivity of findings from this survey question. Firstly, 90% of respondents were mothers, and therefore the findings should be contextualised as being largely the views of mothers. Also, as noted in chapter 1, Gregory et al. (1995) found that the perspectives of young deaf people themselves about their communication with family members were less positive than those of their parents. This survey did not collect the views of young deaf people and therefore it is not possible to say whether their views would have been at odds with the survey respondents. However, the possibility that this may be the case should be borne in mind, and will be referred to again during this thesis. Closely related to this is the fact that respondents may have variable expectations of what constitutes high quality of communication in relation to their deaf child. Some may have benchmarked with hearing children whereas others may have related their judgement to a different expectation for deaf children generally. Without evidence from other sources, such as a control group of responses relating to hearing children, it is not possible to assess this possibility.

Comparisons between family members

Exploration of closed-question responses to the Quality of Communication Question (Appendix 3 [section 2 question 1]) reveals that the family member with whom Group 1 deaf children communicated best was deemed to be the mother (chart 4.2) who is, as has already been shown in chapter 1, most likely to work part-time or to do unpaid work at home. This accords with findings of other studies within the substantive literature, as also noted in the same chapter.

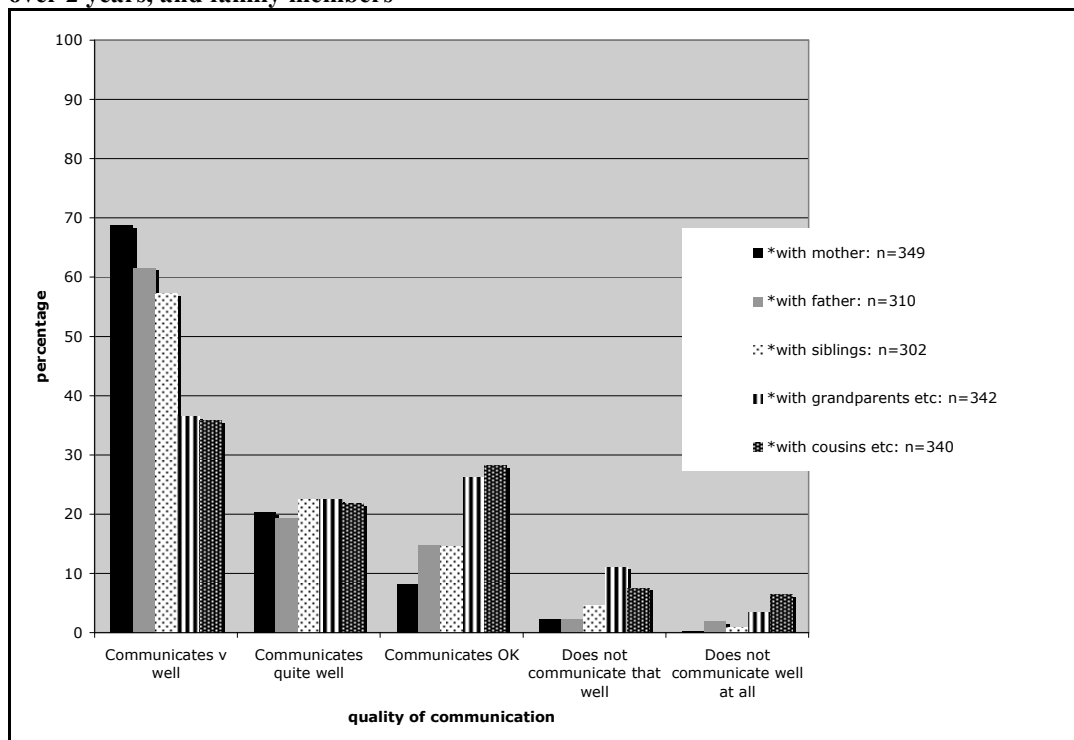
Evidence of a comparatively higher likelihood of communication difficulties between deaf children and their fathers, is borne out by the slightly lower proportions of fathers compared to mothers who were regarded as communicating well. This is in the context of the suggestion made in the previous chapter: that the lower than expected proportion of fathers in full time employment in the Group 1 population may indicate some slight change to the trend in parental roles. Much more detailed exploration would be necessary before drawing conclusions. For example, it may be that the socio-economic skew towards higher household social class may have been a factor within this sample.

Next highest quality of communication was seen to be between the deaf child and siblings. Communication with ‘outer’ family members was rated as relatively low.

Chart 4.3 aggregates the two most positive rating categories and the two most negative categories. While this produces a less nuanced picture, it highlights the following findings:

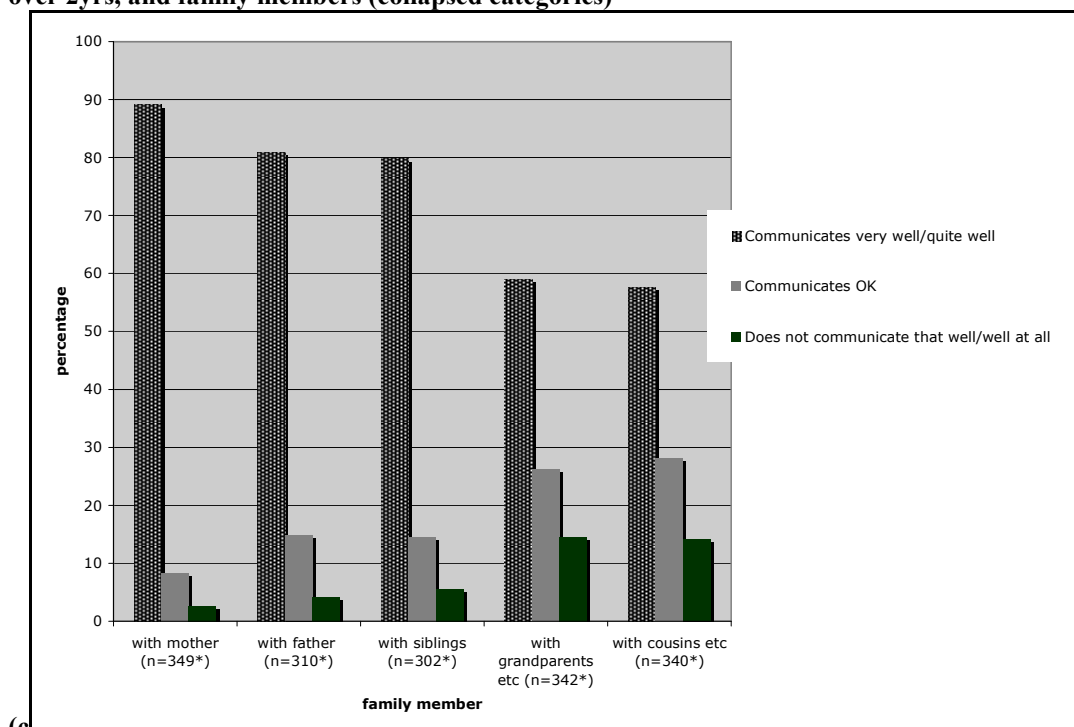
- confirmation that the highest quality of communication was deemed by respondents to be that between deaf child and mother;
- the ratings given to communication with fathers and communication with siblings were broadly similar;
- communication between deaf child and ‘outer’ family members, such as grandparents and cousins, was given a comparatively low rating;
- the ratings given to younger and older ‘outer’ family members were similar.

Chart 4.2: Quality of communication between Group 1 deaf children and young people, aged over 2 years, and family members



* total no. cases where relevant information was provided

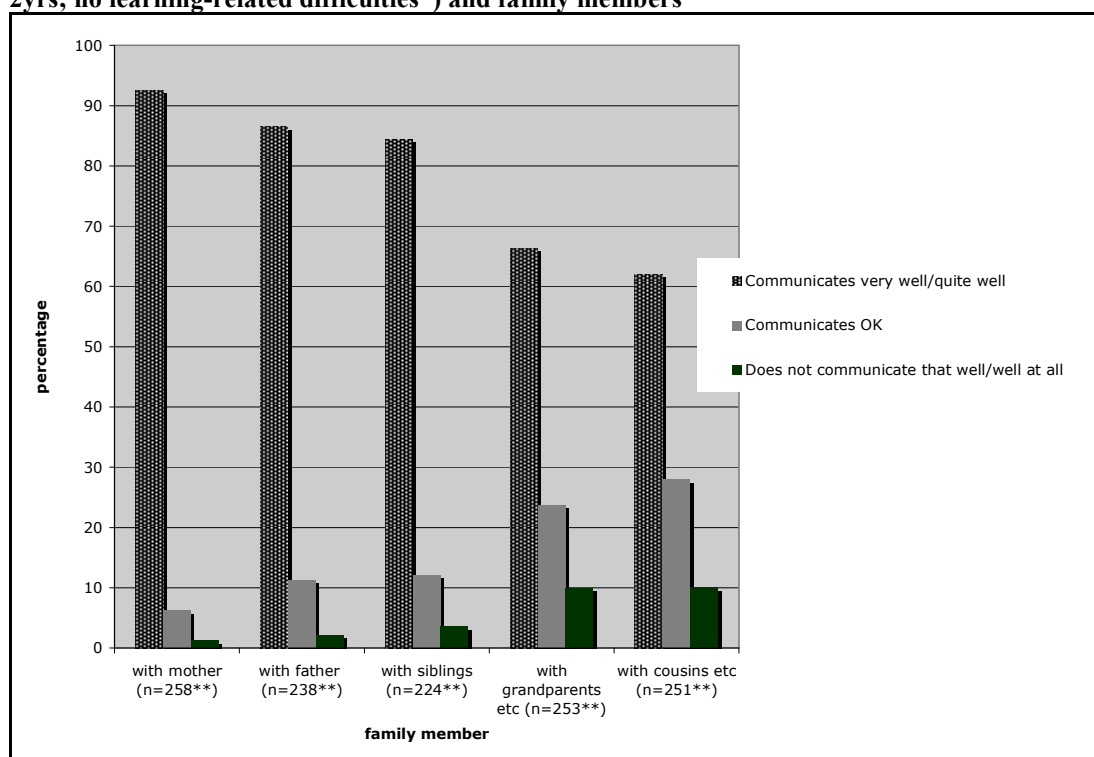
Chart 4.3: Quality of communication between Group 1 deaf children and young people, aged over 2yrs, and family members (collapsed categories)



* total no. cases where relevant information was provided

It is likely that the presence of learning difficulties will have an impact on communication between the deaf child and their family over and above that of deafness. Indeed, as might therefore be expected, communication was deemed to be generally better, across all categories of family members, where no declared learning difficulty was present (chart 4.4). However, the main patterns were the same as those reported above for the whole Group 1 sample, with one minor exception. While the same proportion of older and younger ‘outer’ relatives were reported to have problematic communication, the quality of communication was slightly more likely to be good rather than just OK with the adults

Chart 4.4: Quality of communication between deaf children and young people (Group 1; aged > 2yrs; no learning-related difficulties*) and family members



*includes instances of ‘unlikely to have learning difficulties’ as described in chapter 3 as well as cases where no physical or learning difficulty was reported

** total no. cases where relevant information was provided

Before focusing on data relating to the all-important parent/child dyad, the situation regarding siblings, grandparents and other extended family will first be described.

Communication with siblings

As has been demonstrated, most deaf children were reported as communicating well with siblings: not as well as with either parent, but closest to that with fathers. This is rather different to the pattern reported by young people themselves in Gregory et al.'s (1995) study, which reported better communication with siblings than with fathers. As this study only focuses on parents, it is not possible to say whether the deaf offspring of respondents would have had differing views from their parents.

Some of the literature described in chapter 1 highlighted the fact that siblings can sometimes have a 'special sort of understanding' with the deaf child, in communication terms. The Quality of Communication Question largely comprised closed questions; the one open question asked for comments relating to any family members, and only a small space was given for response (Appendix 3 [section 2, question 1]). While most respondents did not make comments about the quality of communication specifically between the deaf child and siblings in this limited space, a few did highlight a special communication relationship at this point, or within one of the other open responses:

'If other people don't understand what he is saying, his sister usually knows, not us.'
(profoundly deaf child, primary school level)

'X's older sister is his best interpreter.'
(moderately deaf child, primary school level)

'My deaf child has the advantage of an older deaf brother communicating with him in sign language and an older hearing brother who actively encourages him to speak, dance and listen to music...He is a great help to us and interprets for us...(My deaf child) is an outgoing, confident child because of this.'
(severely deaf child, primary school level)

In one case, the closeness of two deaf siblings' communication was so special that it excluded their mother, whose first language was not English:

‘Mother sometimes feels isolated when X and Y [her sister] can communicate – and they seem to have their own “little world” and she’s not part of it.’
(severely deaf child; secondary school level)

There were also some examples where the quality of sibling communication was reported with some qualification:

‘siblings lose patience with X, but it is getting better with time.’
(moderately deaf child, primary school level)

‘I feel siblings would benefit from children’s sign classes.’
(severely deaf child, primary school level)

Thus again there is some similarity with the literature, as well as evidence of diversity in experience within the population, which more in-depth study could explore.

Communication with grandparents and other extended family

As shown above, the general picture in relation to quality of communication with ‘outer’ family members was relatively poor. Gregory et al.’s (1995) study singled out evidence of barriers to communication with grandparents for special mention, given the special significance which the grandparent/grandchild relationships can have within families, as mentioned in chapter 1). There was no specific Family Survey question about the quality of communication with grandparents, per se, although ‘grandparents’, along with ‘uncles’, were given as prompting examples within the closed question about adult ‘outer’ family members (Appendix 3 [section 2, question 1]). As with siblings, some comments about communication with grandparents were volunteered in the open comment space at

the end of this question, as well as in the question about languages used with grandparents.

There was an interesting variety within the small number of comments proffered. Two were positive because of shared experience of deafness/shared language:

‘Both grandparents on mother’s side are deaf, so BSL is used regularly.’
(moderately deaf child, primary school level)

‘He communicates well with his papa because he is deaf.’
(severely deaf child, primary school level)

Most common among grandparent-related comments were responses which expanded on barriers to communication. Interestingly, one comment gave a very different perspective to Beazley and Moore’s (1995) example, cited in chapter 1, where age-related acquisition of hearing loss was positively used by a grandfather to develop a bond with his granddaughter. In the Family Survey example, such late onset of hearing loss was actually given as an example of a communication barrier:

‘Communication problems as elderly grandparents become more hard of hearing.’
(cochlear implanted child, secondary school level)

Some comments describe the fact that grandparents efforts to communicate were limited: either specifically in relation to use of sign language or generally:

‘Paternal grandma has basic BSL but only key words.’
(moderately deaf child, primary school level)

‘(Grandparents use) some basic BSL. No one else has done more than basic signing in the family.’
(profoundly deaf child, primary school level)

‘Grandparents sometimes need an interpreter to understand X...’
(moderately deaf child, secondary school level [with learning disability])

‘(Grandparents use) occasional gesture, but no specific signing.’
(profoundly deaf child, secondary school level)

‘X’s grandmother finds it difficult to communicate with him.’
(severely deaf, preschool level)

‘Grandparents forget about Y’s condition.’
(moderately deaf, primary school level)

Evidence so far suggests an image of a deaf child in the centre of a series of concentric communication circles, with strongest communication represented by the most inner circle – the family members who have most daily contact with the deaf child. This picture was given more depth by fourteen of the respondents, who made comments to that effect within the open section of the Quality of Communication Question. Again, the responses related to a spectrum of levels of hearing loss among the deaf children concerned; in this case: 4 mild, 5 cochlear implanted, 3 moderate and 2 severe. Examples of typical responses are as follows:

‘As X normally misses out of normal conversation he has to ask to repeat/confirm conversation hence communicates less with other members of family than his parents.’
(mild hearing loss, primary)

‘If it’s someone seen often it’s easier for X.’
(cochlear implant, secondary school level, learning disability)

‘More of a problem with people he does not know.’
(moderate hearing loss, primary school level)

‘If the other adults & kids understand her, if not gets frustrated.’
(severely deaf, preschool level)

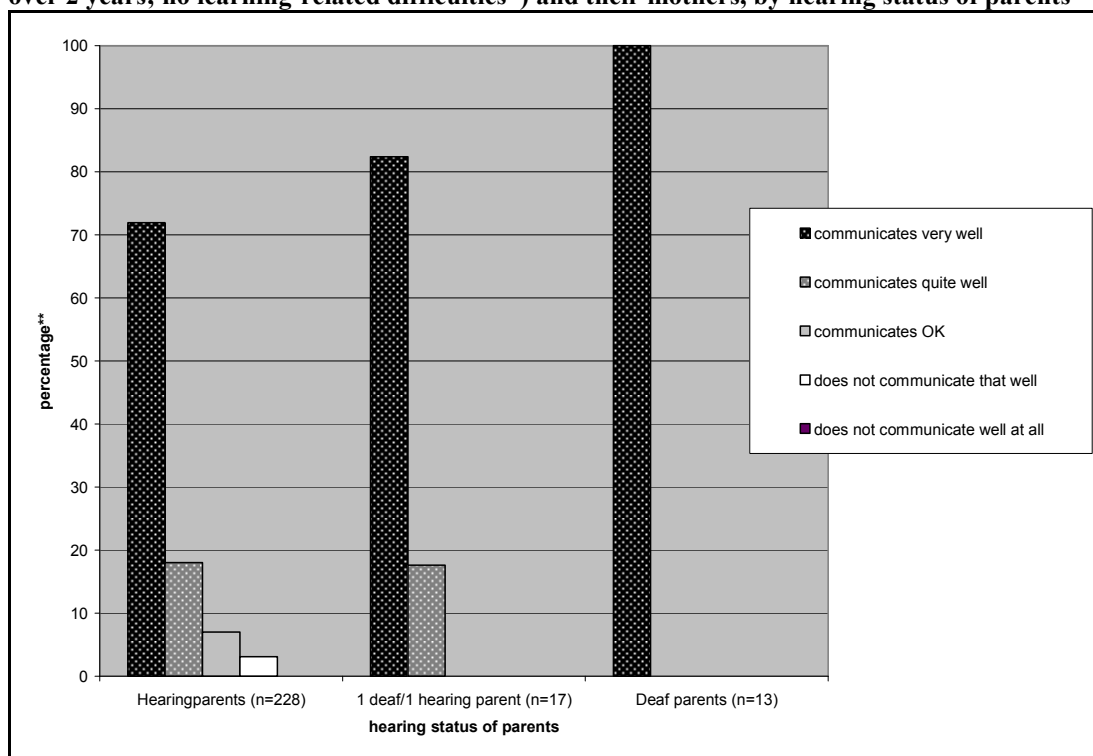
Deaf parents and deaf siblings

Deaf parents

As noted in chapter 1, research studies have demonstrated that communication between deaf children and their parents tends to be relatively unproblematic in deaf families, the environment being more geared towards the linguistic, social and practical situations of deaf people. Indeed, all 13 families where both parents were deaf (or were deaf single parents), within the group considered in chart 4.5¹, reported the highest category of communication quality with their deaf children ('communicates very well'), compared to a more varied pattern among hearing parents. In 1 deaf/1 hearing parent situations, the picture was, perhaps unsurprisingly, in-between. In a separate survey question, parents were asked to report any barriers to discussion with their deaf child about interests, events and helping with homework. This question will be referred from now on as the 'Discussion Question' (appendix 3 [section 3 part 8]). Twenty three percent of hearing parents¹ (n=232) reported barriers of some kind, specifically relating to deafness, whereas all deaf parents¹ (n=13) reported no difficulties. Again, the 1 deaf /1 hearing parent situation was in between, with only 2 out of 18 parents (11%) reporting a deafness-related barrier. Therefore the findings are consistent with the high levels of communication in deaf families which have already been demonstrated in other studies.

¹ Deaf children in Group 1; aged over 2 years; no stated learning disabilities; excluding 'not applicable' and nil responses re hearing status and quality of communication

Chart 4.5: Quality of communication between deaf children and young people (Group 1; aged over 2 years; no learning-related difficulties*) and their mothers, by hearing status of parents



* as defined in chart 4.4

** total no. cases where relevant information was provided

However, the numbers of deaf parents are so low that caution is needed in drawing conclusions from these data alone – particularly in the light of the limitations to the Quality of Communication Question, as already noted above. Furthermore, as discussed in chapter 1, it has been shown that early access to fluent language is the prime factor in high achievement, rather than the hearing status of parents, per se. Pre-school situations will be discussed later in this chapter, but 55% (58) of hearing parents of Group 1 severely deaf/profoundly deaf/cochlear implanted school-age children with no learning disabilities also reported both the highest category of communication between deaf child and mother and that there were no deafness-related difficulties hindering the specified discursive situations.

The language(s) use by the mothers in these 58 cases was explored, in addition to the following other variables: main language(s) used at home; gender; ethnicity; deaf child's first language; age of onset of deafness; cause of deafness; type of school placement; household social class and highest level of qualification of mother. Data shows diversity within this group in all categories of variable. A

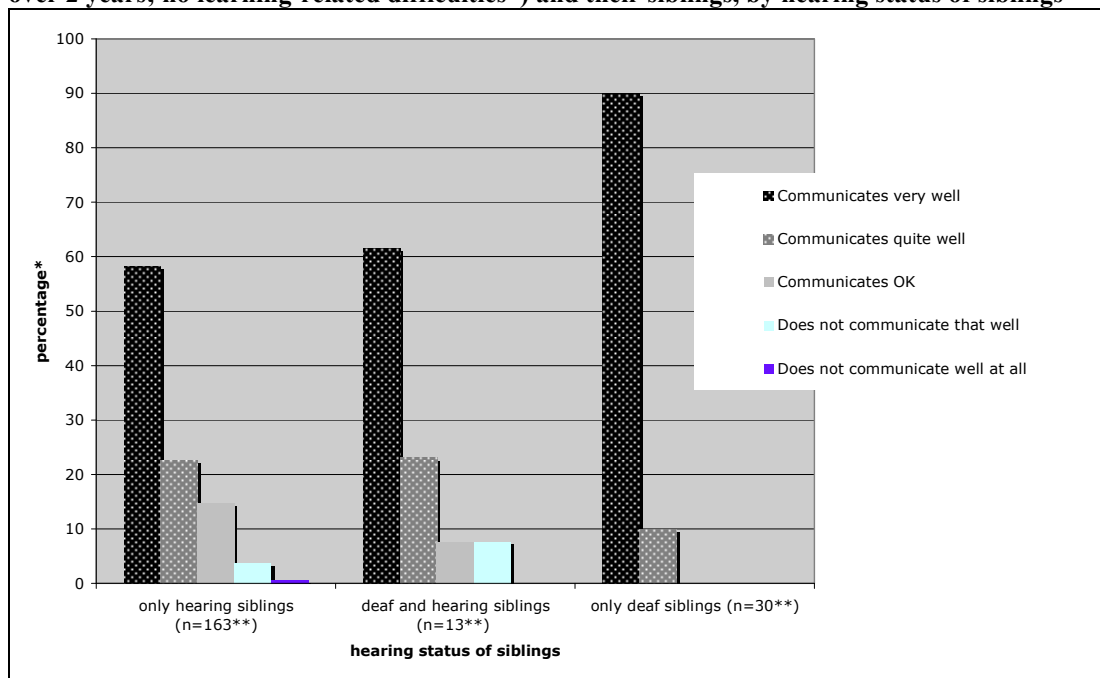
comparator sub-group of hearing parents was identified, where key parent/child communication situations had been reported as more problematic. Again these were parents of Group 1 severely deaf/profoundly deaf/cochlear implanted school-age children with no learning disabilities. In these cases, respondents had reported that communication with mothers was not as high quality as that represented by the ‘communicates very well’ category, and that there were difficulties in the parent/child discussion situations. There were only 15 cases in this sub-group but, although there were some differences between the two sub-groups, as might be expected because of the small size of the sub-sample, again, diversity was the most striking pattern among the results. Detailed data for both groups is shown in Appendix 4.

Therefore, while the data bear out previous evidence that deaf parents tend to consistently have high levels of communication with their deaf children, the findings do not explain the differences in communication quality found in parent/child dyads among hearing families. It seems reasonable to hypothesise that, for deaf children of hearing families in Scotland, the interface between their individual linguistic aptitudes and skills, and the breadth and depth of linguistic support available to them and their families, will be significant factors. As the early years period has been identified as the key time for access to fluent language, these issues will be further explored in a separate section, below, which focuses on this developmental stage.

Deaf siblings

As has been shown earlier, the quality of communication between the deaf children and their siblings was rated by respondents at around the same level as that with fathers. Chart 4.6 shows the picture when hearing status of siblings is factored into the situation. Again the number of situations of ‘deaf only’ siblings is small but, again, the high rating of communication quality is pronounced. Further exploration of the thirty ‘only deaf siblings’ situations shows that 25 of the 30 parents were hearing, and that there was a diverse range, among the deaf child subjects concerned, of hearing loss levels and of languages/language modes used between the siblings.

Chart 4.6: Quality of communication between deaf children and young people (Group 1; aged over 2 years; no learning-related difficulties*) and their siblings, by hearing status of siblings



* as defined in chart 4.4

** total no. cases where relevant information was provided

In one or two cases, additional comments were volunteered about the psychosocial benefits of having deaf siblings:

‘He has been helped, I think by the fact that his sister is profoundly deaf also, so he has not felt that he is “alone” with the handicap’
(profoundly deaf, secondary school level)

Returning to parents, the next sub-section will explore, in more depth, data from both the Quality of Communication Question and from the Discussion Question, in order to obtain as nuanced a picture as possible of the communication in the crucial deaf child/parent dyad.

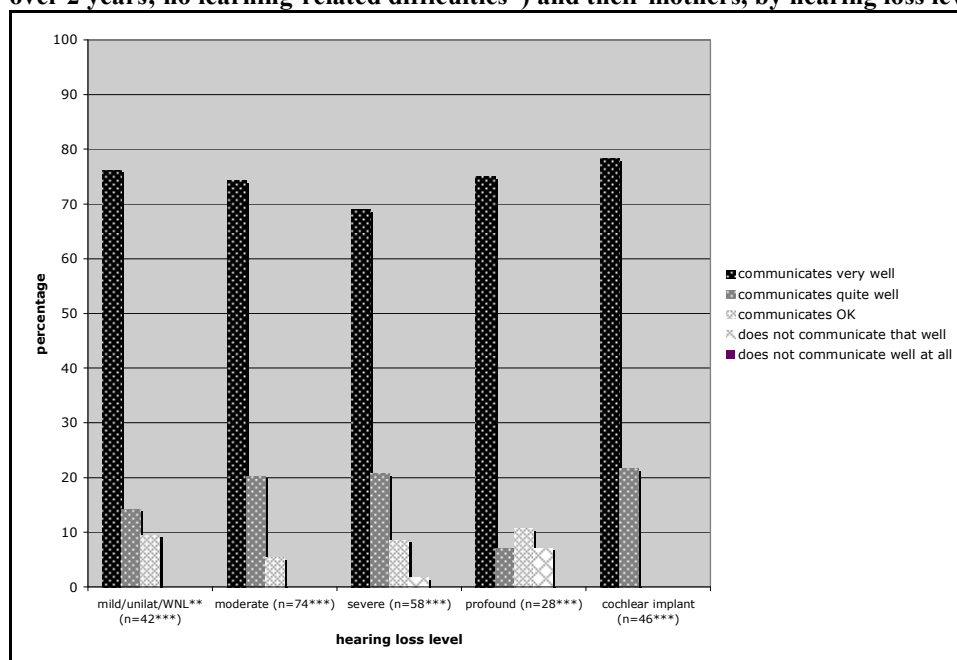
The parent/deaf child dyad

Effect of hearing loss level

Chart 4.7 focuses again on children over 2 years old who had no reported learning disabilities, and demonstrates the quality of reported communication with mother, broken down by hearing loss level of the child. Starting on a positive note, there were no instances at all of the lowest category of communication with mother ('does not communicate well at all').

The most positive pattern among the hearing loss level groups is that for cochlear implanted children. This group had the highest proportion of 'communicates very well' responses, with all responses being in the top two categories. By contrast, a proportion of responses relating to other hearing loss level groups were in the 'ok' or 'does not communicate that well' categories. The profoundly deaf group shows the highest level of 'does not communicate that well'; however, this actually only represents two children, both of whom are primary aged children living in homes where at least one spoken language other than English is used.

Chart 4.7: Quality of communication between deaf children and young people (Group 1; aged over 2 years; no learning-related difficulties*) and their mothers, by hearing loss level of child



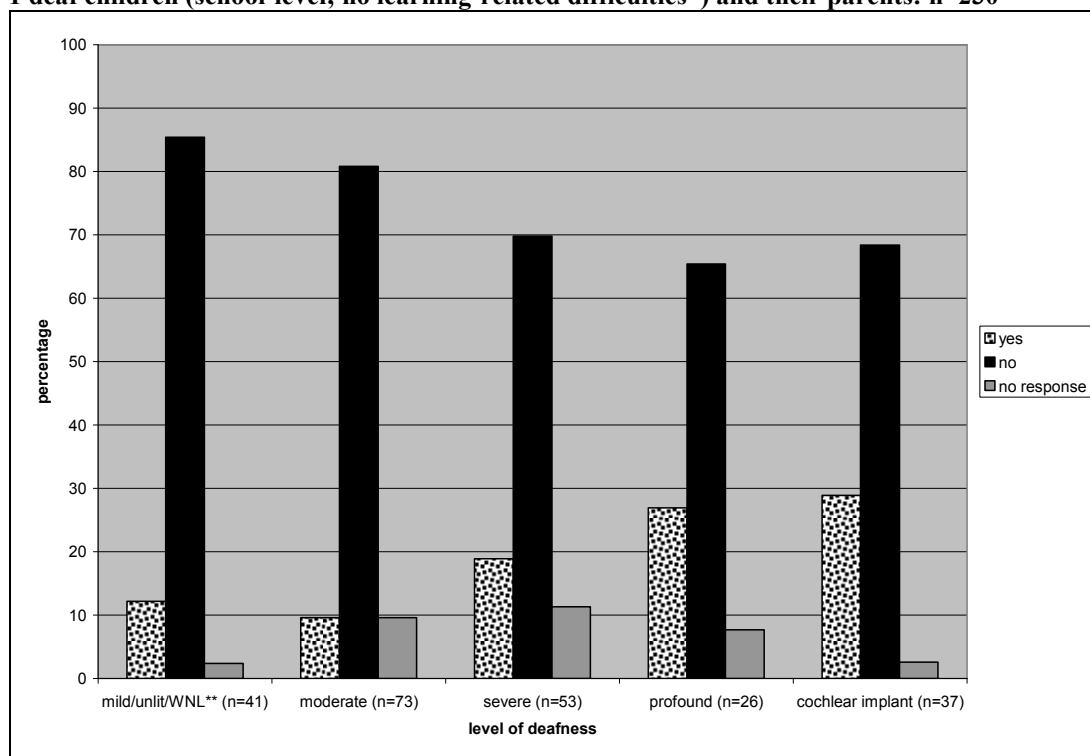
* as defined in chart 4.4 ** within normal limits *** total no. cases where relevant information was provided

A more nuanced picture about meaningful communication within the crucial parent child dyad was derived from responses to the Discussion Question (Appendix 3 [Section 3, part 8]). As already described, this question was more clearly targeted at key parent/child conversation situations within the home (the day's events, homework support and the child's own interests) and specifically related to the impact of deafness on these situations. A sub-question asked respondents to report on the impact of deafness on the aggregated discussion situations, rather than on each situation separately. As homework support is included in this, only school-age children will be considered in reporting data from this sub-question.

Chart 4.8 shows that, after excluding preschool children, and those with reported learning difficulties, the majority of parents reported no difficulties relating to deafness which prevented communication - and this was true across all hearing loss levels. However, as might be expected, those with children in the severe/profound/cochlear implanted groups were more likely to report difficulties: 11% (12) of the combined mild/moderate groups compared to: 19% (10) of the severe group; 27% (7) of the profound group and 29% (11) of the cochlear implanted group. Thus the situation for cochlear implanted children here seems to be more negative than for all other hearing loss groups, which is in direct contrast to responses to the Quality of Communication Question, as just illustrated above.

While it is not possible to be sure why there is an apparent contradiction here, one can speculate that it may reflect the types of questions involved. As already noted, the Quality of Communication Question was limited by the lack of guidelines as to how respondents should benchmark the largely relative term 'quality'. It may conceivably have been the case that parents were measuring quality in relation to the pre-implant situation. This, in itself, would not preclude the possibility that there were current barriers relating to deafness which were preventing or hindering discursive interactions.

Chart 4.8: Presence of difficulties relating to deafness which prevent discussion between Group 1 deaf children (school-level; no learning-related difficulties*) and their parents: n=230***



* as defined in chart 4.4

** within normal limits

*** total no. cases where relevant information was provided

It should be said that parents of school-age implanted children, at the time this survey was undertaken, would have been unlikely to have had the fullest benefit from cochlear implantation, in terms of early infant implantation following neo-natal diagnosis of deafness. Also, more recent developments in multi-channel implantation technology have increased their potential effectiveness (Thoutenhoofd et al., 2005). As there was a sample skew towards the child having BSL as a main language at home; an additional argument may be that some of the children may consequently not have been deemed to have had sufficient immersion in spoken English. However, as was pointed out in chapter 1, even among those children who are implanted as babies, there is some recent research evidence of diversity in linguistic aptitude and preferences, and in the quality of access to informal and formal learning. It appears reasonable to assume that the reports of deafness-related barriers to parent/child discussion across the spectrum of hearing loss levels may at least partly reflect such diversity among the Family Survey population. As the discussion situations specified in the survey question are the kind of discursive

interactions which are fundamental to a child's acquisition of informal knowledge and skills from parents, it seems pertinent to explore this possibility in more depth.

The small number of respondents reporting deafness-related difficulties preventing discussion, and the lack of other key detail, such as the length of time since cochlear implant 'switch on' date, precludes conclusive comment. Numbers are even smaller when the situation of each hearing loss level group is further broken down. However, exploration of the language situations of the 'profound', 'cochlear implanted' and 'severe' groups does show diversity among languages and languages modes used by the mothers with their deaf children (Appendix 5). This again coincides with literature, cited in chapter 1, which demonstrates that factors other than the actual language/language mode, per se, are most significant to the quality of communication exchange between parent and child. In addition, no clear pattern emerged when household socio-economic status (by Standard Occupational Category) was explored.

Difficulties preventing discussion

As has already been noted, one factor which stands out is that all respondents within households with two deaf parents, or with a deaf single parent, were consistent in reporting 'no difficulties' in the specified discursive situations, as well as reporting the highest level of quality of communication with mothers. However, it was shown also that this doubly-positive report pattern also applied to a high proportion of hearing parent households, without it being possible to evidence the reason(s) for the diversity among the hearing household population.

Respondents who had reported difficulties preventing discussion were invited to provide brief details via an open question. As all respondents from all-deaf parent households reported no difficulties, all comments relate to hearing-parent households, and therefore provide more depth to these situations.

Thirty seven out of the 40 parents who had reported difficulties also provided comments, which were coded and categorised inductively, under three headings:

‘language/conceptual problems’; ‘communication skills problems’ and ‘other’. The majority related to problems with language and/or conceptual understanding.

Examples of each category are as follows:

Language/conceptual problems examples (22 instances):

‘Lack of understanding’
(moderately deaf; spoken English used with mother)

‘Sometimes she finds it difficult to express herself because she doesn’t have the language/words’
(moderately deaf; English plus another spoken language used with mother)

‘Lack of language, makes it difficult to express things sometimes’
(severely deaf; spoken English plus limited signing used with mother)

‘Mum does not know BSL, does not know English. However learning both these languages now.’
(profoundly deaf; spoken language other than English [plus limited BSL and English] used with mother)

‘He is unable to express himself fully. Our communication is very limited.’
(profoundly deaf; spoken English and gestures used with mother)

‘Limited understanding of spoken language’
(cochlear implant; spoken English used with mother)

‘Finding it very difficult to explain to X about her changing body – development.’
(cochlear implant; English and gestures used with mother)

Communication skills problems (7 instances):

‘Understanding of speech’
(hearing loss ‘mild/unilateral/within normal limits’; spoken English used with mother)

‘Level of hearing’
(severely deaf; English and SSE used with mother)

‘Communication skills’
(profoundly deaf; spoken English used with mother)

‘Have to use good deaf awareness skills to communicate with X’
(cochlear implant; English and limited signing used with mother)

‘When I don’t have enough “sign” to explain something and X
can’t understand what I’m saying; e.g “what’s a complex
carbohydrate”
(cochlear implant; BSL and English used with mother)

Other issues (11 instances):

‘Rest of family talking at the same time as X’
(moderately deaf; spoken English used with mother)

‘Requirement for 1:1 more than with our other children’
(severely deaf; spoken English used with mother)

‘The younger brother age 10 helps him do the homework’
(severely deaf; spoken language other than English used with
mother)

Again, further details would be needed before being able to either objectively measure the extent of the difficulties described or to pinpoint the key factors causing them. However, these comments, in particular those relating to language/conceptual problems, provide greater richness to the report that a sizeable minority of deaf children, without learning disabilities, in hearing families, were perceived by parents to be experiencing language and communication limitations to key informal learning and socialising situations provided by parents at home. The diversity in languages and modes is noteworthy among the children referred to in these examples.

Table 4.4 shows the breakdown of category of comment by hearing loss level. The numbers in each category are very small, but it is clear that, apart from the mild/unilateral/within normal limits group, the majority of comments in each hearing loss level band fall within the category of ‘language/conceptual understanding problems’.

Table 4.4: Explanation of difficulties relating to deafness which prevented discussion between deaf child (Group 1; school-age; no learning-related difficulties*) and parents, by hearing loss level (n=33)**

| | Language/conceptual problem comments | Communication skills comments | Other types of comment |
|---|---|--------------------------------------|-------------------------------|
| Mild/unilateral/within normal limits | 1 | 2 | 2 |
| Moderate | 3 | | 2 |
| Severe | 5 | 1 | 1 |
| Profound | 4 | 2 | 1 |
| Cochlear implant | 5 | 2 | |
| Total incidences | 18 | 7 | 6 |

*‘learning-related difficulties’ = reported difficulties likely to affect learning, as categorised in chapter 3

**excluding 6 cases where information on hearing loss level was not provided

When ‘language(s) used with mother’ data are factored in, it can be seen that language and conceptual problems feature clearly across all languages/modes. Little more can be said, given the small numbers in some groups, other than the fact that this again ties in with the fact that language/language modes, in themselves, do not seem to be causal factors in barriers preventing discussion.

Table 4.5: Explanation of difficulties relating to deafness which prevented discussion between deaf child (Group 1; school-age; no learning-related difficulties*) and parents, by language(s) used with mother (n=34)**

| | Language/conceptual problem comments | Communication skills comments | Other types of comment |
|--|---|--------------------------------------|-------------------------------|
| English/Scottish | 10 | 4 | 5 |
| Other spoken language(s) | 2 | | 1 |
| English and limited sign/gestures | 5 | 1 | 1 |
| Sign Supported English | 1 | 1 | 1 |
| English and BSL | 2 | | |
| Total incidences | 20 | 6 | 8 |

*‘learning-related difficulties’ = reported difficulties likely to affect learning, as categorised in chapter 3

**excluding 3 cases where information about language(s) used with mother was not provided

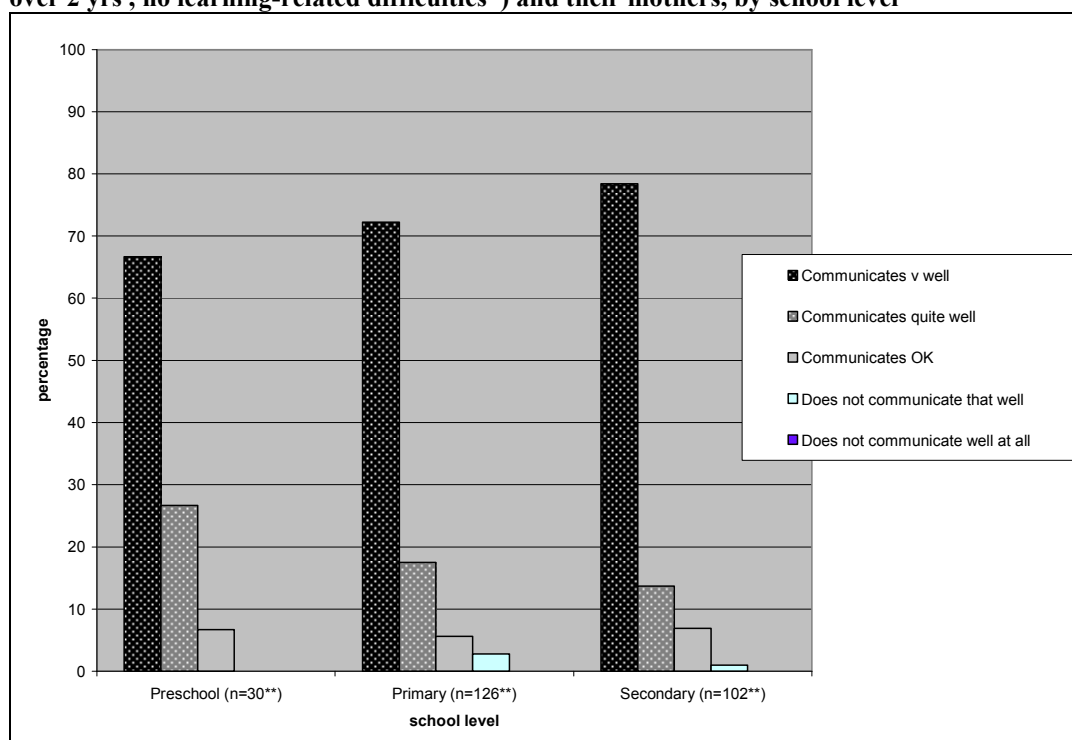
Appendix 6 provides a matrix, giving a fuller breakdown of cases by hearing loss level and language(s) used with mother.

So far data has related to a relatively wide age range of 2-18 years. In this final section of this chapter, analysis will focus on the linguistically significant early years.

Communication in early years

Chapter 1 highlighted the fact that communication in early years has been shown to be a significant predictor of success in all areas of a child's development. Charts 4.9 and 4.10 show a breakdown, by school level², of results relating to communication with mothers and with fathers. It shows that, at preschool stage, the vast majority of communication was rated as good – particularly communication with mothers. However, there was a relatively low level of 'communicates very well' with both mothers and fathers, compared to other age groups.

Chart 4.9: Quality of communication between deaf children and young people (Group 1; aged over 2 yrs , no learning-related difficulties*) and their mothers, by school level

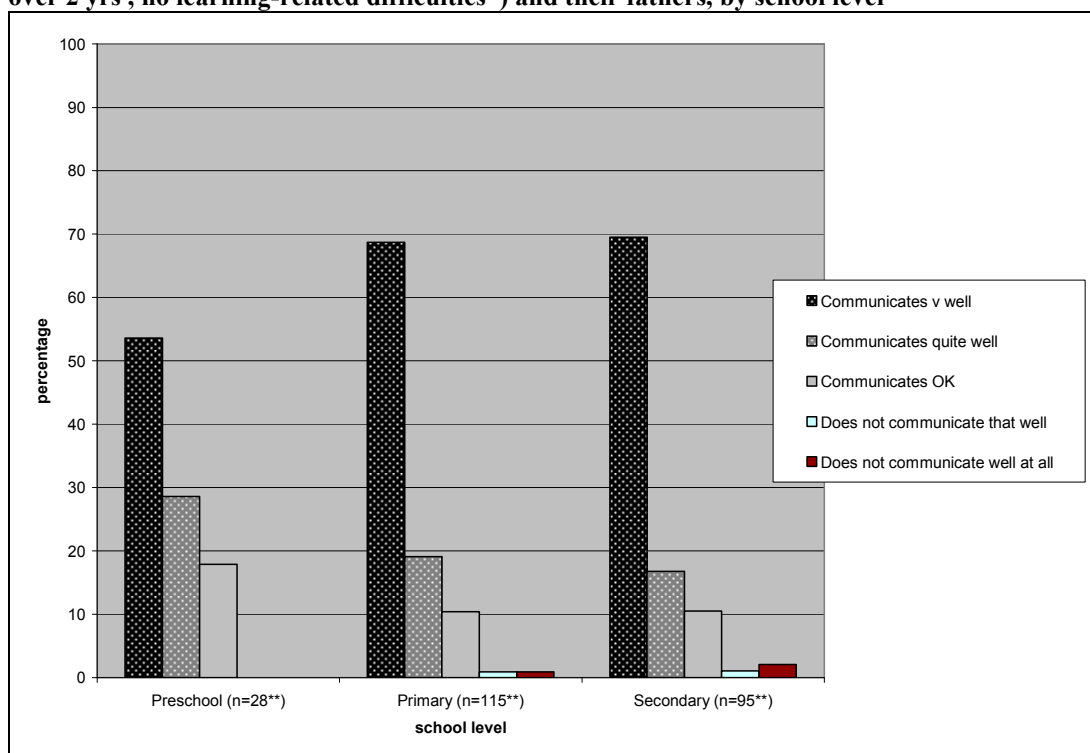


* as defined in chart 4.4

** total no. cases where relevant information was provided

² Children of 1 year 11 months or less have been excluded, because of the relatively low expectations of language levels of all infants in this age-range

Chart 4.10: Quality of communication between deaf children and young people (Group 1; aged over 2 yrs , no learning-related difficulties*) and their fathers, by school level



* as defined in chart 4.4

** total no. cases where relevant information was provided

It has already been pointed out that the validity of this particular survey question was limited by the lack of equivalent information about communication between hearing children and family members. In addition the question did not add explanatory instructions about how responses should be benchmarked in relation to age and hearing status. The fact that the proportion of ‘communicates very well’ goes up relative to age may simply reflect an age-related rise in any child’s sophistication of language. Furthermore, there were only, respectively, 30 and 28 preschool cases within the category being used for the analysis in charts 4.9 and 4.10, which is too small a number on which to base a trend, despite there being a slight skew towards pre-school level children within the Family Survey population. Therefore it is not possible, from this evidence alone, to be sure of the exact significance of the relatively low proportions of deaf children reported as communicating very well with their mothers at preschool level - and of the even lower proportion with their fathers.

In order to find further evidence, within the data, on the preschool situation, all open responses relating to preschool deaf children's communication with their parents were also explored. In particular, comments relating to the following topics were perused: communication within the family; languages used with parents; discursive interactions with parents and 'any other information'. Twenty out of the 31 respondents with deaf preschool children, who were over 2 years old and had no stated learning difficulties, had made at least one relevant comment. Comments for each case were summarised and the summaries coded. A matrix was devised, which also factored in: the child's hearing loss levels; the hearing status of parents; languages used by the parents with the child, and key socio-economic information (including highest educational level of mother). Comments describing concerns about parent/child communication were made in sixteen cases; table 4.6a shows all factors for these cases, including a selection of the comments. Relatively neutral/positive comments were made in another four cases (table 4.6b); a fifth instance related to one case also categorised in the previous table.

Table 4.6a: Nature of limitations in communication between deaf preschool children (over 2 years old, with no learning disabilities*) and their parents

| Nature of comments | Case no. | Hearing loss level of child | Hearing status of parents | Household SOC^^ classification | Mother's highest level of qualification | Languages/modes used by parents with deaf child | |
|---|----------|-----------------------------|---------------------------|--------------------------------|---|--|--|
| Communication limitation (no specific reason offered) | 1 | Severe | Hearing | Working | CSEs etc | Spoken English + limited SSE | 1. 'Try to discuss, but only learning sign. It's hard to get my child to understand' 2. 'Have to keep words simple, repeat familiar sayings/activities. Only starting to put 2/3 words together' 3. 'Difficulty in communicating what he wants or has done at nursery' 4. 'it is very difficult to know how much to push & what you can expect (specialist staff) to do. I think where a deaf child attends, staff should undergo training so at least one can sign with the child ' 5. 'Finds it hard to concentrate...I think if X would learn to lipread or (use) sign language it would be beneficial' 6. 'Limited vocabulary in both BSL and English' 7. 'X is just learning Makaton, but it is at a basic level so communication is difficult' 8. 'Sometimes if she is frustrated and we don't understand what's wrong or what she wants, that can be upsetting for both her and us.' 9. 'Due to his age (2yrs 7 months) and language, we are unsure of how much is understood – he is able to demonstrate to us some things he understands' |
| | 2 | Severe | Hearing | Managerial | Highers etc | Spoken English | |
| | 3 | Severe | Hearing | Managerial | HNC etc | Spoken English + some limited signing | |
| | 4 | Slight^ | Hearing | Managerial | Degree etc | Spoken English + limited signed English (dad only) | |
| | 5 | Slight^ | Hearing | Working | CSEs etc | Spoken English | |
| | 6 | Profound | Hearing | Managerial | Degree etc | Spoken English/BSL/gestures | |
| | 7 | CI** | Hearing | Managerial | Degree etc | Spoken English + Makaton | |
| | 8 | CI** | Hearing | Unclassified | CSEs etc | Spoken English and SSE | |
| | 9 | Slight^ | Hearing | Managerial | Degree | Spoken English | |
| Communication limitation – late diagnosis | 10 | Severe | Hearing | Unclassified | Degree etc | Spoken English + some limited signing | 10. 'Limited speech and understanding due to late diagnosis' |
| | 11 | Severe | Hearing | Managerial | Degree etc | Spoken English + some SSE | 11. 'Limitations of receptive and expressive language due to language delay (late diagnosis) |
| Communication ltd – recent diagnosis | 12 | Mod | Hearing | Intermediate | CSEs etc | Spoken English | 12. 'He is not quite yet 4 so hopefully in time he will improve'. |
| Speech limitation | 13 | Severe | Hearing | Unclassified | CSEs etc | Spoken English | 13. 'X's speech' |
| Communication limitation inferred | 14 | n/k | Hearing | Managerial | HNC etc | Spoken English | 14. 'Quiet background, no distraction, get attention, may have to repeat and gestures.' |
| | 15 | CI** | Hearing | Managerial | Degree etc | BSL/SSE/ Spoken English | 15. 'Basic communication' |
| | 16 | CI** | Hearing | Intermediate | Highers etc | Spoken English (BSL+ Eng pre-implant) | 16. 'She is making good progress with her implant, but her understanding of many everyday situations is very behind that of her hearing peers.' |

* as defined in chapter 3; **cochlear implant; ^ mild/unilateral/within normal limits; ^^ Social Occupational Categories (see chapter 3)

Table 4.6b: Other types of comments

| Nature of comments | Case no. | Hearing loss level of child | Hearing status of parents | Household SOC^^ classification | Mother's highest level of qualification | Languages/modes used by parents with deaf child |
|----------------------------------|----------|-----------------------------|---------------------------|--------------------------------|---|---|
| Most c'cation is with mum | 17 | n/k | Hearing | Intermediate | Highers etc | Other spoken lang/Eng/signs |
| | 2* | severe | Hearing | Managerial | Highers etc | Spoken English |
| Positive with some qualification | 18 | n/k | I deaf/1 hearing | Unclassified | No info | Spoken English |
| | 19 | CI** | Deaf | Intermediate | Highers etc | BSL |
| Generally positive | 20 | CI** | Hearing | Intermediate | CSEs etc | Spoken English |

* same case as in table 4.6a

**cochlear implant

^^ Social Occupational Categories (see chapter 3)

It is hardly surprising that deafness poses a linguistic challenge for hearing parents, and these findings highlight the fact that, for some parents, there appear to have been significant linguistic barriers between themselves and their deaf children at this crucial stage. As noted in chapter 1, effective communication between parents and their deaf children is 'easily the best predictor of success' in a deaf child's development (Marschark, 2007:5) and, therefore, reports of late diagnosis and of poor language, understanding and vocabulary are matters of concern. It should be reiterated that these were children who were 'just deaf', without additional learning difficulties, and that, therefore, one might have hoped for indications of better language and communication levels between parents and their deaf children in these cases.

Looking more closely at table 4.6, the diversity of levels of hearing loss among the children, of the languages/language modes used by parents and of the socio-economic status of families is striking. Respondents who made the comments were geographically spread throughout 14 local authority regions of Scotland, so it is possible that the diversity in languages/language modes could, in part, reflect diversity in language policies of services, in addition to parents having made decisions based on individual knowledge and experiences. However, as has been pointed out in chapter 1, the likelihood of parents having had access to a spectrum of high quality assessments and resources which fully include BSL, and the use of signs in support of English, is very slight. Only 3 out of these 14 local authority services

had a member of teaching staff with advanced level BSL. As it is also known that only 3 other school professionals (such as Communication Support Workers) in Scotland had advanced level BSL at that time (Grimes, 2008), this is particularly significant for hearing families, who are highly unlikely to have had contact with the language prior to the birth of a deaf child in the family.

Therefore the presence or absence of BSL, or some form of signs in support of English, in the individual permutations of languages used, cannot be assumed to have been based on thorough assessments of aptitude and abilities. The lack of consistency of service language policy and resourcing means that the choices are more likely to have been made on relatively ad hoc bases: a combination of local service policy, local service resources and individual parental knowledge and experience. In one case, it can be seen that parents had opted for the use of Makaton as a form of Sign Supported English but, as this system is designed primarily for hearing children and adults with learning disabilities, it is surprising that it was chosen as a sign supported English system for a cochlear-implanted deaf child with no learning disabilities; it suggests a rather individually-improvised arrangement, which may conceivably have been contributing to the communication limitations being experienced by the parent.

There was only one case, in the category as defined in chart 4.6, where both parents were deaf and where their child was at preschool level, and therefore no comparisons can be drawn between the experiences of deaf parents and hearing parents. Nevertheless, as has already been addressed in this section, the fact that the deaf child, in this case, was reported as communicating ‘very well’ with mother was typical of the rating for all ages of deaf children of deaf parents, as has already been demonstrated above.

Summary comment

In summary, bearing in mind the various limitations to the data, a family communication picture emerges which broadly corresponds to relevant research literature. For example: the central role of the mother/deaf child dyad; the correspondence between the position of members within the family circle and the quality of communication with deaf child, and the consistency of reports of higher quality communication in deaf child/deaf parent and deaf child/deaf sibling dyads, compared to the diversity within deaf child/hearing parent dyads and deaf child/hearing sibling dyads. Findings which indicate new avenues for further study include: the possibility of slight increase in the extent to which fathers spend additional time with their deaf children, and apparent contradiction, in relation to cochlear implanted children and young people, between reports of high quality deaf child/hearing mother communication and evidence of barriers to key discursive interactions within the same parent/child dyads.

It appears that the greatest challenge is to clearly identify what hearing parents need to do in order to guarantee the consistency and quality of access to fluent language which seems to be provided by deaf parents – especially in the early years. More information is needed, particularly about the interface between: language and communication in the family; linguistic assessments which have been/are being used to explore the deaf child's non-verbal as well as verbal aptitudes and abilities, and the breadth and depth of the bilingual/multimodal spectrum of available linguistic support resources. As was indicated in chapter 1, there are few studies which have focused on communication within family settings, and therefore this evidence confirms the need for such nuanced and multi-faceted exploration.

Having explored communication between deaf children and family members, the next chapter will focus on: data relating the social life of deaf children and young people in the sample, in terms of friendships and participation in out-of-school activities; their access to cultural events and activities; and the parental role in facilitating the independence of their deaf adolescent children.

Chapter Five: Findings Relating to Friendships, Participation in Activities and Independence

This chapter focuses on the two research questions which address deaf children's participation in social and cultural activities as well as parental restrictions on the development of independence. Both research questions consider the impact of deafness-related issues and, as the social activities data is the most complex, this chapter is the most extensive. Brief summaries are therefore provided at the end of each chapter section.

In line with Young et al.'s position, as noted in chapter 1 (Young et al., 2008:43), in the analysis of findings it is not assumed that deafness itself is intrinsically a risk factor for disadvantage, but, rather:

‘...deafness in a range of familial, social and institutional contexts may interact with variables and processes that render its disadvantaging effects more likely.’

It should also be noted that all population samples and sub-samples analysed in this chapter exclude cases where the children and young people concerned have specific difficulties (as defined in chapter 3) which have impact, or are likely to have impact, on learning. This is in order to, as far as possible, remove the risk that the presence of such difficulties may have a confounding effect on the identification of deafness-related issues.

Research Question 2: Using parent reports, what are the extent and nature of deaf children's participation in social life and in structured activities outside school, and of the degree to which deafness-related issues impact on their participation?

Friendships

As already noted, alongside family relationships, quality friendships are significant in children's developing sense of belonging. In chapter 1, the impact of educational inclusion policies and legislation on the hearing status of deaf children's friendship networks was discussed; in particular, issues around the ever-increasing likelihood that deaf children will spend their school-time with hearing, rather than deaf, peers. It was also pointed out that there is a paucity of research on the detail of deaf children's friendships.

Therefore the Family Survey included a group of questions on deaf children's relationships with both deaf and hearing peers. Respondents were asked: to rate the respective strength of friendships with both groups; to indicate if any limitations to relationships with hearing children were related to deafness issues, and to make respective comments about relationships with both groups. As in Gregory et al.'s (1995) study, it is acknowledged that parents may vary in their conceptions of the term 'friendship', something which is likely to impact on the generalisability of findings relating to parental judgements about strengths of friendships – particularly as the perspectives of young people themselves are not included in this study. Also, the concept of 'limited' friendships is open to interpretation and, inevitably, spans a spectrum of degrees of limitation. Bearing all of this in mind, it is argued that respondents' comments, which elucidated the judgements, have enabled a more nuanced exploration of friendship quality. The questions will be referred to, respectively as the 'Hearing Friendships Question' and the 'Deaf Friendships Question', the texts of which are set out in Appendix 7.

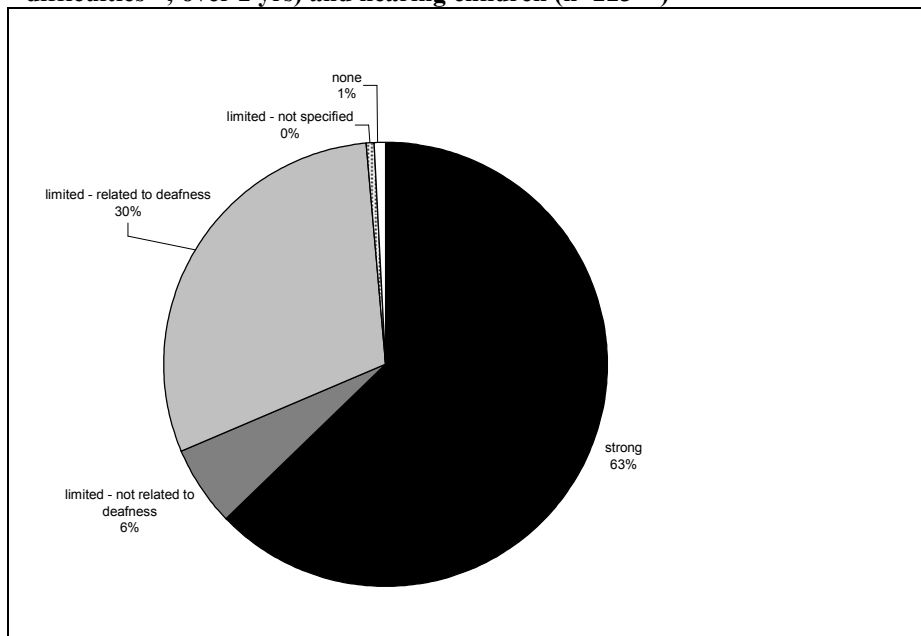
Group 1 children over the age of 2 years have been included for this section on friendships – a sub-sample comprising 263 children and young people. Eighty four of the sub-sample of parents made comments which explicated their responses. Comments were coded on the basis of emergent themes. As the impact of educational inclusion is a contextual issue, for each comment, the type of school placement is given in addition to hearing loss level and school level of child.

Friendships with hearing children

Basic analysis showed that only two children/young people in the sample were reported to have no friendships at all with hearing peers. Both of these children used at least one spoken language other than English at home, were primary school age and reportedly had no friends with deaf children either; one was severely deaf and attended mainstream school, and the other was profoundly deaf and attended a school for deaf children. Both children had been in the UK for a relatively short time and both had experienced a series of moves to different countries prior to that; the parents of one were asylum-seekers. It seems likely that the linguistic and cultural complexities of their situations may have been significant in terms of limitations to opportunities and capacities to make friends with either deaf or hearing children.

Almost two thirds (63%) were reported to have strong friendships with hearing children. However, chart 5.1 also indicates that the hearing friendships of almost a third (30%) were limited by factors relating to their hearing loss.

Chart 5.1: Strength of friendships between deaf children (Group 1; no learning-related difficulties *; over 2 yrs) and hearing children (n=223)**



* as defined in chart 4.4

** total no. cases where relevant information was provided

As a main focus of this research question is the level of impact of deafness-related issues, special attention is paid here to revealing details which were said to limit friendships with hearing peers. Forty seven parents made comments to this effect.

Twenty of the comments related to barriers evident in the two-way process of communication. Some parents located the comment in their child's difficulties, with a knock-on effect being marginalisation or exclusion:

'If my son had more language he could and would be more confident making friends.'
(primary school level [mainstream with unit]; cochlear implant)

Others within the twenty focused more on the attitudes of the hearing children as the starting point. The following quote is also representative of a small number of comments which mentioned the effect of stigma:

'Peer group do not have the patience to wait and re-explain what they have already told X. Also some children do not want to play with X as she has a classroom assistant in class therefore she is different or stupid.'
(primary school level [mainstream]; moderate hearing loss)

Other themes which emerged were: specific difficulties with group situations; problems making new friends; particularly small circles of friends; other parents' attitudes; less hearing friends with increasing age; less comfort with hearing than deaf friends and the effect of school being located outwith the area. The themes inevitably overlap.

The data was broken down by school placement, hearing loss level, parental hearing status and first language of child. Although, as in other situations, widely varying numbers among categories preclude generalisations, some interesting patterns were revealed.

In general, the greater the hearing loss level of the child, the less the likelihood of strong friendships with hearing children and the greater the likelihood of deafness-related difficulties. The proportion of cochlear-implanted children with strong hearing friendships was nearer to that of severely deaf children than to profoundly deaf children, but they also were most likely to be reported as having difficulties (table 5.1a). This could be seen to resonate with Bat-Chava and Deignan's (2001) findings that implantation positively affected hearing friendships, but that language and communication restrictions to relationships were still common.

Similarly, the more intensive the level of support in school placement, the less likelihood that the pupil was reported as having strong friendships with hearing peers, and, in terms of mainstream-related placements, the more likelihood that deafness-related difficulties were reported (table 5.1b).

Table 5.1 Proportions of deaf children (Group 1; no learning-related difficulties*; aged over 2 years) who have strong friendships with hearing children and deafness-related limitations to friendships with hearing children

a) By hearing loss level**

| | mild/unilateral/within normal limits (n=40) | moderate (n=69) | severe (n=51) | profound (n=22) | cochlear implant (n=37) |
|----------------------------|---|-----------------|---------------|-----------------|-------------------------|
| strong friendships | 83% | 67% | 59% | 36% | 51% |
| limited (deafness-related) | 10% | 29% | 33% | 36% | 49% |

b) by school placement**

| | Mainstream with no in-class support (n=33) | Mainstream with in-class support (n=129) | Mainstream with unit (n=41) | School for deaf children (n=9) |
|----------------------------|--|--|-----------------------------|--------------------------------|
| strong friendships | 76% | 68% | 46% | 33% |
| limited (deafness-related) | 21% | 26% | 46% | 44% |

* as defined in chart 4.4

**percentages relate to the column heading rather than to the row

There was insufficient evidence of difference between deaf and hearing parents to comment on the effect of parental hearing status. In the case of first language, those with English as first language were more likely to have strong hearing friendships than those whose first language was reported as BSL or BSL/English (67% [127] vs 42% [10]). Only two out of ten children with spoken

languages other than English had strong hearing friendships and, as reported earlier, two had no hearing friends at all.

Friendships with other deaf children

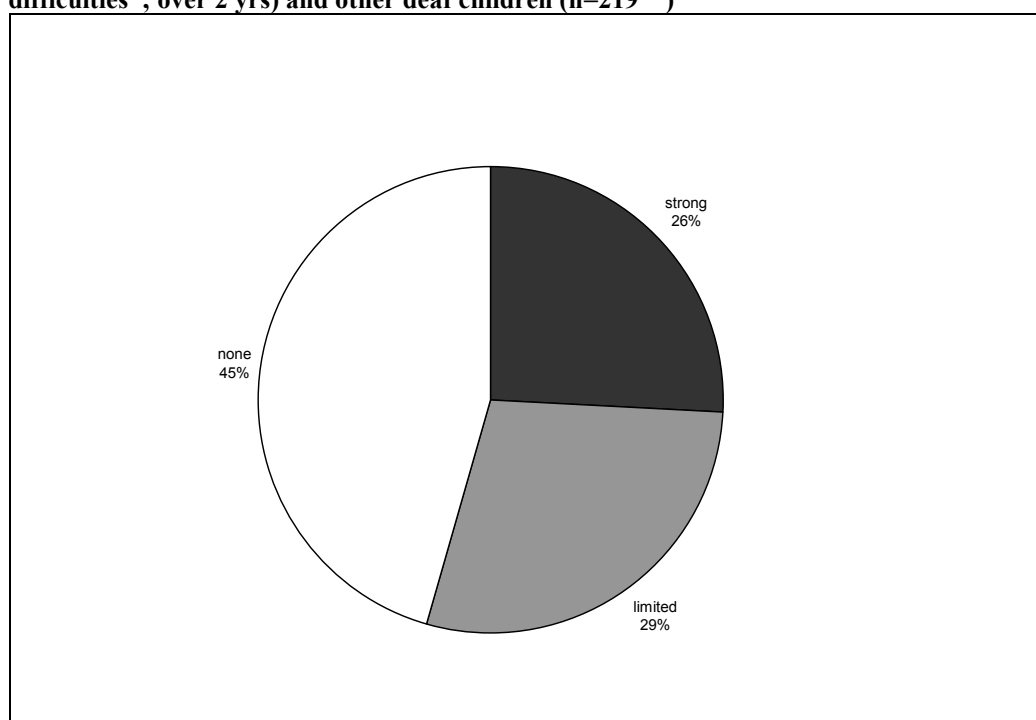
Chart 5.2 shows the picture of strengths of friendships with other deaf children. In contrast to the situation with hearing children, 45% (100) did not have any relationships with deaf children. Of these 100 children and young people, the majority (59%) were in mainstream school environments without specialised units, and had slight or moderate hearing losses. However, almost a third (31%) of those with no deaf friends in mainstream had a severe or a profound loss or had a cochlear implant. The majority of parents who commented about their child's lack of deaf friends explained that there were no deaf children in their local area. Given the widely-dispersed nature of the Scottish population, outwith the urban central belt, this is perhaps not surprising. As in Bat-Chava and Deignan's study (2001), some parents added comment that they would have liked their children to have the opportunity to meet other deaf peers:

‘X does not know any deaf children, something we regret very much.’
(primary school level [mainstream]; cochlear implant, rural area)

A few noted that their deaf child had had opportunities to develop friendships with deaf peers, but had rejected the possibilities:

‘He does not want to mix with other deaf people although we have tried to encourage this.’
(secondary school level [mainstream with unit]; severe hearing loss)

Chart 5.2: Strength of friendships between deaf children (Group 1; no learning-related difficulties*; over 2 yrs) and other deaf children (n=219)**



* as defined in chart 4.4

** total no. cases where relevant information was provided

Out of those with limited friendships with deaf peers, other emergent themes were: deaf friendships being limited to school; deaf friendships being limited to siblings, and distance from deaf friends. Where relationships were described as strong, the special significance of deaf friendships was described – tallying with data from other studies, as discussed in chapter 1. In the first example, below, the respondent implies that deaf networks are a normalising experience for her child, compared to, using Antia et al.'s (2002) terms, a sense of 'visitorship', among hearing peers. The second raises the interesting question of what form of communication is being described. In this case the child attended a primary unit which excluded the use of sign language, and yet the implication is that the informal communication between peers was gravitating naturally to visual-spatial communication.

'X is more relaxed with other deaf children, she does not feel she is different.'

(secondary school level [mainstream with unit]; profound hearing loss)

‘Bonds are stronger than with hearing children. There is a shared experience. Less pressure to produce speech. Use more sounds and gestures and make less effort with language so more relaxing for child’
(primary school level [mainstream with unit]; cochlear implant)

When data is broken down by hearing loss level it is clear that the greater the hearing loss among children in this sub-sample, the more likelihood there was of strong deaf friendships, and the less likelihood that they would have no deaf friendships at all (table 5.2a). Interestingly, the cochlear implanted children were most likely to have deaf friendships and least likely to have none.

There was an even stronger relationship between the level of specialist support in school placement and the proportion of strong friendships with deaf pupils: the more intensive the potential support level within the placement (and the greater potential for meeting other deaf children), the more likely that the child had strong deaf friendships (table 5.2b). In terms of mainstream-related placements, the less the support level, the greater the likelihood that child would have no deaf friends at all. As regards placements in schools for deaf children, bearing in mind that there were only 11 children involved, none were in the ‘limited’ deaf friendships category: all were described as having either strong friendships or no friendships. Of the two reported as having none, one was just over 2 years old and the other was one of the two cases described earlier, where there were cultural, linguistic and relocation complexities.

Table 5.2 Proportions of deaf children (Group 1; no learning-related difficulties*; aged over 2 years) who have strong friendships with deaf children and deafness-related limitations to friendships with deaf children

a) By hearing loss level**

| | mild/unilateral/within normal limits (n=39) | moderate (n=65) | severe (n=50) | profound (n=24) | cochlear implant (n=37) |
|---------------------|---|-----------------|---------------|-----------------|-------------------------|
| strong friendships | 8% | 17% | 26% | 38% | 51% |
| limited friendships | 26% | 28% | 34% | 29% | 27% |
| no friendships | 68% | 55% | 40% | 33% | 22% |

b) by school placement**

| | Mainstream with no in-class support (n=31) | Mainstream with in-class support (n=126) | Mainstream with unit (n=42) | School for deaf children (n=11) |
|---------------------|--|--|-----------------------------------|---------------------------------------|
| strong friendships | 0% | 13% | 67% | 82% |
| limited friendships | 19% | 34% | 24% | 0% |
| no friendships | 81% | 53% | 10% | 18% (2) |

* as defined in chart 4.4

**percentages relate to the column heading rather than to the row

As might be expected, all but one of the deaf children in all-deaf-parent households were reported to have strong friendships with other deaf children. The one report of limited deaf friendships reflected a concern that their child did not have a sufficiently wide circle of deaf friends:

‘Only 4 deaf children in his year in mainstream school. Like him to go to Deaf School to have more friends his age.’
(secondary school level [mainstream with unit]; severely deaf)

As a contrast, only 23% (44) of deaf children in all-hearing-parent households had strong friendships with deaf peers. ‘Mixed’ 1 hearing/1 deaf parent households, had the highest proportion of limited deaf friendships (57% [8]), but also the lowest proportion of strong ones (21% [3]). Apart from wide disparity in numbers within the group, the differences are bound to reflect the differing hearing loss levels between the groups of children involved: 2 out of the 3 ‘mixed’ status children had mild/moderate losses.

It has already been shown that there was a link between the level of hearing loss and the likelihood of use of a sign language. The predictable link between the level of use of sign language and the level of strong deaf friendships was demonstrated by the fact that over twice as many children who used BSL to some extent had strong deaf friendships compared to those who used English (55% [11] vs 22% [42]). This correlates with research literature which has shown a link between level of deafness, the use of sign language and the number of/desire for deaf friendships (chapter 1). However, two whose first language was BSL/English were reported as having no deaf friends at all. One proved to be just over the age of

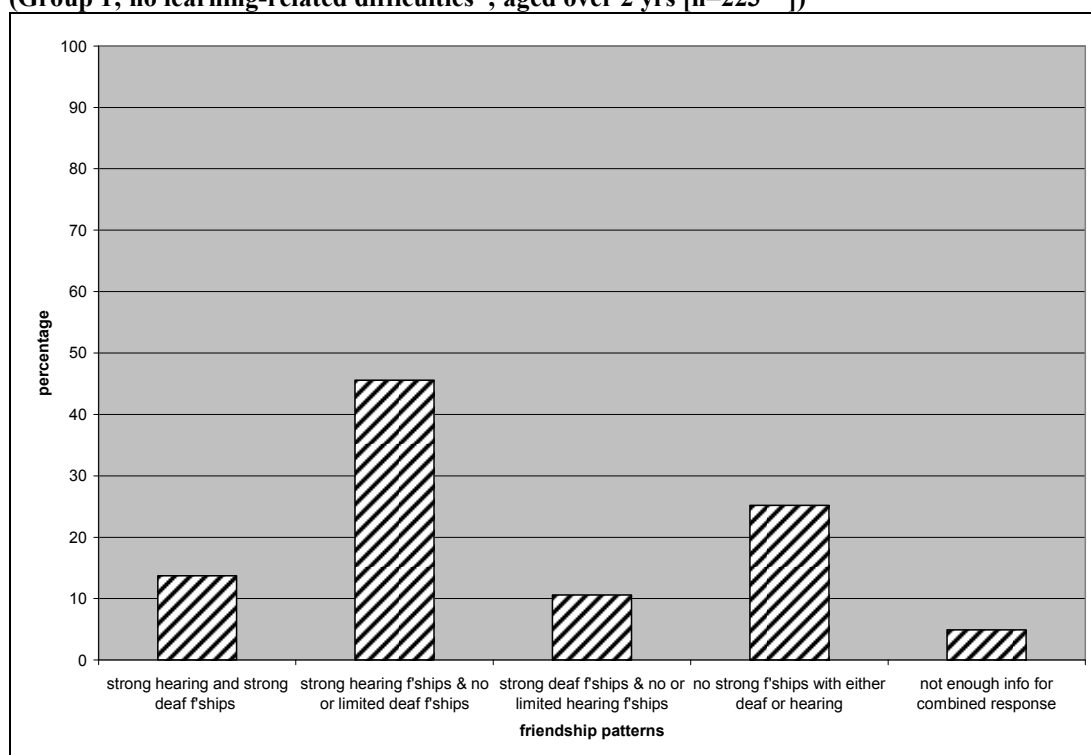
2 years, with hearing parents who expressed concern over their own levels of BSL. The other was a cochlear-implemented child, who lived in a particularly remote rural area. Geographical remoteness and/or lack of other deaf children in the area also appeared to be factors among 5 out of the 7 with limited deaf friendships. A typical comment is as follows:

‘[friendships with other deaf children are limited by]...area required to cover to meet other deaf children. Also peer group is limited in area’
(secondary school level [mainstream]; cochlear implant; BSL first language)

Balance of relationships with deaf and hearing peers

Data on the strength of relationships with both deaf and hearing children was combined to provide a rough description of the balance of each child’s hearing/deaf friendships strengths, within four constructed categories, as revealed in chart 5.3.

Chart 5.3: Strength of friendships with deaf and hearing children among deaf children of respondents (Group 1; no learning-related difficulties*; aged over 2 yrs [n=223])**



* as defined in chart 4.4

** total no. cases where relevant information was provided

Strong friendships with both deaf and hearing peers

As can be seen from chart 5.3, a relatively small proportion of the sub-sample were reported as having strong friendships with both deaf and hearing peers. Among different hearing loss levels, cochlear implanted pupils had the highest proportion of children and young people in this category (30% of 37 pupils), over twice the proportion of profoundly deaf children (13% of 24 pupils) and at least three times the proportion of those in other categories. This would appear to tally with parents' hopes, expressed in Archbold et al.'s (2002) study, that implantation would provide optimal opportunity for a deaf/hearing balance in peer relationships. As one parent stated:

'My daughter is very outgoing and confident and embraces hearing and deaf children alike.'
(primary school level; cochlear implant; mainstream school with unit)

Those who had BSL or BSL and English as their first language(s) were almost twice as likely to have this pattern of friendship as those whose first language was English (12.1% [23] vs 22% [6]), thus also resonating with the tendency of the eight implanted adolescents in Wald and Knutson's (2000) study to favour a bilingual-bicultural identity. Again it must be stressed that a more 'oral' trajectory may be likely for children more recently implanted.

Mainstream schools with specialist units for deaf children were developed in the 1980s as part of the move away from special schools into what was then described as 'integrated' rather than 'inclusive' education (Kumsang & Moore, 1998). While the 'inclusion agenda' has driven their development generally towards a resource base rather than teaching base model, they still potentially provide a social meeting place for deaf children as well as an educational resource, within a mainstream setting. Therefore it is perhaps unsurprising that pupils in this type of placement (mostly severe, profound or cochlear implanted pupils) were most likely to be reported as having strong friendships with both hearing and deaf peers (31% of 42 pupils).

Although not to the same extent as schools for deaf children, schools with units can be relatively long travelling distances from pupils' homes, reflected in the number of comments indicating that the strong friendships with deaf children were based in school-time only:

‘...[friendships with deaf children have] developed whilst at school. No contact with deaf children really takes place outside the school environment.’
(primary school level [mainstream with unit]; cochlear implant;)

Strong hearing friendships/no or limited deaf friendships

As one might have expected, the lower the level of hearing loss, the more likely it was that deaf children's strong friendships were reported as being mostly, or all, with hearing children (table 5.3a). Similarly, the less the concentration of specialist provision within the school placement, the greater the likelihood of this friendship pattern (table 5.3b)

Table 5.3: Proportions of deaf children (Group 1; no learning-related difficulties*; aged over 2 years) who have strong friendships with hearing children and no or limited friendships with other deaf children

a) by hearing loss level**

| Mild/unilateral/within normal limits (n=40) | Moderate (n=69) | Severe (n=52) | Profound (n=24) | cochlear implant (n=37) |
|---|-----------------|---------------|-----------------|-------------------------|
| 73% | 51% | 44% | 21% | 22% |

b) by school placement**

| Mainstream with no in-class support (n=33) | Mainstream with in-class support (n=129) | Mainstream with unit (n=42) | School for deaf children (n=11) |
|--|--|-----------------------------|---------------------------------|
| 70% | 57% | 14% | 0% |

* as defined in chart 4.4

**percentages relate to the column heading rather than to the row

Those with English as first language were more than three times as likely to have the pattern as those who had BSL or BSL and English (52% [99] vs 15% [4]). In terms of hearing status of parents, no respondents at all from all-deaf-parent households reported the combination, compared to 42% of all-hearing-parent households and 37% of 'mixed' households.

Strong deaf friendships/no or limited hearing friendships

The situation in terms of this combination was, in most cases, a predictable reverse of the previous category. On closer inspection, it is interesting that less than a fifth of profoundly deaf children in the sample were reported as having stronger friendships with deaf than with hearing children. On the other hand, one might possibly have expected less than 22% of those with cochlear implants to have this pattern, given the expectation that greater access to speech sounds might encourage closer relationships with hearing children (table 5.4a).

Similarly, given the expectation that unit/resource base placement provides a bridge to social, as well as educational, contact with hearing peers, one might have expected the proportion with this pattern would have been lower than 36% (15). It may hint that, while placement in this type of provision has been shown to correlate with a relatively high percentage of deaf/hearing balance of friendships, for some deaf children it may fulfil a stronger social-cultural resource for those who prefer the company of other deaf people:

‘As my daughter has got older she feels more comfortable with children her own age who also have a hearing loss.’
(secondary school level [mainstream with unit]; severe hearing loss)

Table 5.4: Proportions of deaf children (Group 1; no learning disabilities*; aged over 2 years) who have strong friendships with other deaf children and no or limited friendships with hearing children

a) by hearing loss level**

| Mild/unilateral/within normal limits (n=40) | Moderate (n=69) | Severe (n=52) | Profound (n=24) | cochlear implant (n=37) |
|---|-----------------|---------------|-----------------|-------------------------|
| 0% | 6% | 15% | 17% | 22% |

b) by school placement**

| Mainstream with no in-class support (n=33) | Mainstream with in-class support (n=129) | Mainstream with unit (n=42) | School for deaf children (n=11) |
|--|--|-----------------------------|---------------------------------|
| 0% | 3% | 36% | 36% |

* as defined in chart 4.4

**percentages relate to the column heading rather than the row

Exploration of language data showed that, as predictable, those with BSL or BSL/English as first language(s) and/or with deaf parents, were much more likely to

have a friendship pattern weighted towards deaf, rather than hearing, children (table 5.5)

Table 5.5: Proportions of deaf children (Group 1; no learning-related difficulties*; aged over 2 years) who have strong friendships with other deaf children and no or limited friendships with hearing children

a) by first language(s)**

| Spoken English (n=190) | BSL or BSL & English (n=27) |
|------------------------|-----------------------------|
| 7% | 33% |

b) by hearing status of parents**

| All-hearing-parent households (n=200) | All-deaf-parent households (n=10) | 1 deaf/1 hearing parent (n=15) |
|---------------------------------------|-----------------------------------|--------------------------------|
| 9% | 40% | 13.3% |

* as defined in chart 4.4

**percentages relate to the column heading rather than the row

No strong friendships with either deaf or hearing children

Of particular concern are the 25% (57) who reported as having no strong friendships with either deaf or hearing children. Again, likelihood of this situation rose with level of hearing loss, up to 38% (9) of profoundly deaf children. As with the proportion of strong friendships with hearing children, the proportion of cochlear implanted children was nearest that of severely deaf rather than profoundly deaf children (table 5.6a). However, even those with mild and moderate losses had high enough proportions to be worthy of note – respectively, 18%(7) and 26%(18):

‘Children who have normal hearing don’t understand what it is like not being able to hear so they forget to make sure that the hearing impaired child is aware of what’s being said, thus making deaf child not feeling part of the group.’
(primary school level [mainstream]; moderate hearing loss; no deaf friends)

Among school placement types, that of ‘mainstream with in-class support’ had the highest proportion of this friendship category (28%[36]) (table 5.6b), hinting that there may be an issue, for at least some, of falling between two ‘worlds’:

‘Hearing peers become impatient with him. They do not always appreciate the difficulties he has or that he relies quite a lot on lip reading. Forget to speak one at a time etc. One other deaf child at

school (younger). Meeting with other deaf children at NDCS Christmas parties were difficult as the majority signed and he does not. I feel the difficulty is that although severely hearing impaired he is not deaf enough to fit in the deaf community but does not hear well enough to fit easily into the hearing world.’
(primary school level [mainstream]; severely deaf; limited deaf friends)

‘We don’t know any oral speaking deaf children and of course signing deaf children just leaves them feeling alone – very difficult. He would love to meet other oral speaking deaf kids’
(primary school level [mainstream]; moderately deaf; no deaf friends)

Table 5.6: Proportions of deaf children (Group 1; no learning-related difficulties*; aged over 2 years) who have no strong friendships with either hearing or deaf children

a) by hearing loss level**

| Mild/unilateral/within normal limits (n=40) | Moderate (n=69) | Severe (n=52) | Profound (n=24) | cochlear implant (n=37) |
|---|-----------------|---------------|-----------------|-------------------------|
| 18% | 26% | 25% | 37.5% | 27% |

b) by school placement**

| Mainstream with no in-class support (n=33) | Mainstream with in-class support (n=129) | Mainstream with unit (n=42) | School for deaf children (n=11) |
|--|--|-----------------------------|---------------------------------|
| 24% | 28% | 14% | 18% |

* as defined in chart 4.4

**percentages relate to the column heading rather than the row

It was more likely that children who had English as first language were in this friendship category than those who had BSL or BSL/English (26%[49] vs 19%[5]). Only 7 cases of those with spoken language(s) other than English provided enough information for combined categorisation. However, 3 out of the 7 were in this friendship category, as might have been predicted by other evidence about this group so far reported. No children of deaf parents were in this group.

It should be again stressed that a range of degrees is encompassed by comments within the ‘limited friendships’ categories, so some of the comments in this category are a mixture of positive and negative points:

‘X has a good relationship with hearing children but a lot of the time when they are playing he doesn’t hear what they say, which leads to him being “left out” and this causes a lot of frustration.’
(primary school level [mainstream]; moderate hearing loss; no deaf friends)

However, at the other end of the spectrum are some cases which raise the most concern, by the depiction of very isolated children and young people. Two brief profiles of children in this category were drawn earlier. In the first of the following comments relating to two other cases, one young person was, worryingly, reported as being actively bullied:

‘Out of school has no contact with year group. Friends are all younger. Frequently bullied & verbally abused by kids he does not know.’
(secondary school level [mainstream]; severe hearing loss; no deaf friends)

‘X can be very hard to manage at times and can spoil friendships by his behaviour. He has no interaction with deaf children and must get frustrated and left out with hearing children.’
(primary school level [mainstream]; profound hearing loss; no deaf friends)

On a more positive note, many parents mentioned the importance of Deaf Children’s Society regional and national events, as a means of counteracting their children’s lack of access to deaf friendships. As with the examples cited earlier, a few respondents reported their children as feeling marginalised at events if they did not previously have experience of sign language and other children were using it. However, there were at least as many positive reports, whether or not the children/young people concerned used sign language at home:

‘There are no other deaf children in our area. Has met others at NDCS weekends & has enjoyed their company greatly.’
(secondary school level [mainstream]; severe hearing loss)

‘Does not mix every day with other deaf children at school but really enjoys when we get together with (X)DCS.’
(secondary school level [mainstream]; moderate hearing loss)

‘(X)DCS has get-together weekends and X meets other deaf boys. Although the others sign, X enjoys their company’
(secondary school level [mainstream]; severe hearing loss)

As noted in chapter 1, evidence in other research has shown that parents often make considerable effort to facilitate their deaf children’s friendships. Participation in the regional/national reflects this, as do other examples within the data:

‘Difficult accessing close links as school not local. I am able to help with transport to ensure X can socialise with schoolfriends, many other deaf children’s parents may be unable to provide transport.’
(secondary school level [mainstream with unit]; moderate hearing loss)

Friendships: summary comment

In summary, almost all deaf children and young people in this sub-sample had friendships at some level with hearing children. However, nearly a third of these friendships were reported as being limited by communication barriers, and a sizeable minority of this group had relatively slight hearing loss levels. By contrast, almost a half had no friendships with other deaf children, and a sizeable minority of these had relatively significant hearing loss levels.

When hearing/deaf friendship strength profiles were constructed, basic analysis revealed some relatively predictable profiles in terms of hearing loss levels, school placement, first language and parental hearing status, while always indicating diversity. Some patterns emerged which were not so foreseeable. For example, cochlear implanted children were, as the literature suggested, most likely to have been reported as having strong relationships with both deaf and hearing children. However, their profile also revealed generally stronger links to deaf children – a similar pattern to that among children in ‘mainstream with unit’ school placements.

Tensions were apparent in the necessary trade-offs between the benefits and disadvantages of local school mainstream placements versus more specialised ones. 'Mainstream with unit' placements seemed to provide the most opportunity for the development of both deaf and hearing friendships but, particularly in less densely populated areas, long distance from home meant lack of opportunity to naturally carry over friendships with deaf children into out-of-school life. Ninety five percent of the area of Scotland is classed as rural (The Scottish Government, 2008). The data illustrated the isolation experienced by deaf children in more rural areas who are experiencing barriers to communication with hearing pupils while having no accessibility to deaf peers.

However, the 25% who were reported as having no strong friendships with either deaf or hearing children were not confined to rural situations, and most concern was raised about this group generally. While it is acknowledged that there are limitations to the robustness of category definitions, and that they include a spectrum of positive and negative permutations of situations, respondent comments revealed some evidence of serious isolation, where deaf children and young people were apparently 'falling between two worlds' in their social lives. This suggests the need for further consideration, particularly in view of the continued inclusion drive within educational legislation and policy.

Participation in structured activity groups

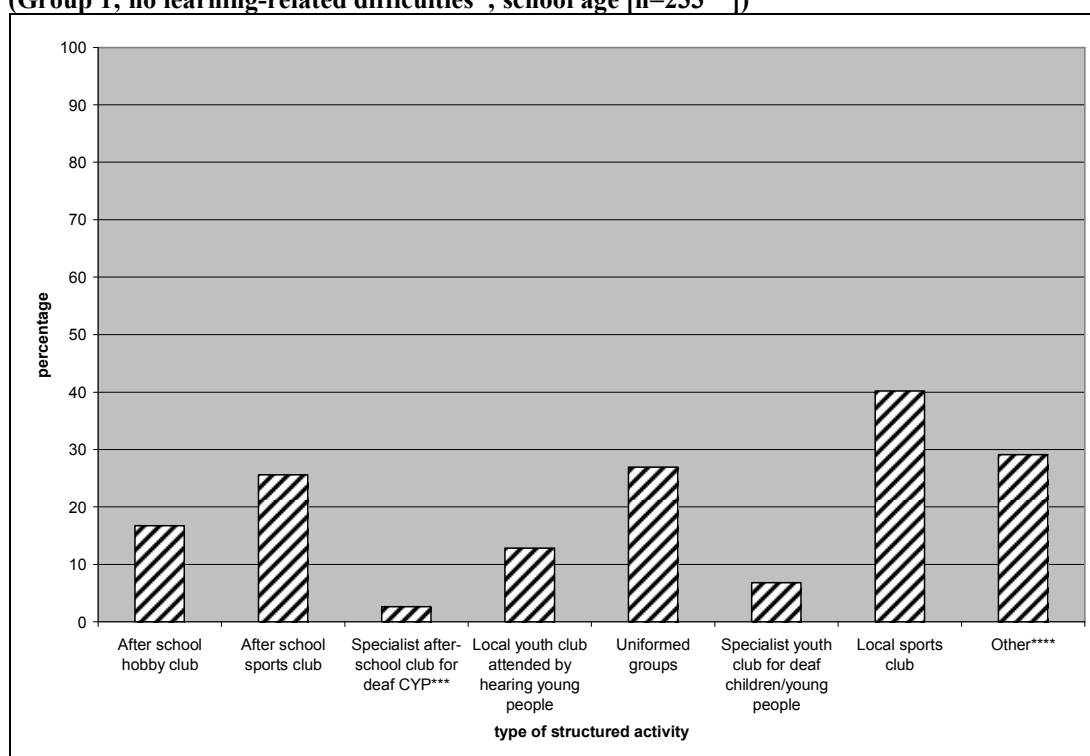
In chapter 1 it was suggested that participation in clubs and structured activities outwith school can have a significant impact on deaf children's experience of school life and social relationships – and in their level of self esteem generally. However, it was also shown that low expectations and communication barriers can be detrimental to their inclusion, leading to a situation where a participating deaf child or young person can end up rather more like a visitor to a group than being its full member.

Two hundred and twenty four of respondents with Group 1 school-aged children who had no learning-related difficulties responded to the question which asked whether or not their children took part in out of school activities. Eighty percent of these said that their child took part in some form of activity. The Family Survey sought information on attendance at a variety of types of mainstream activity clubs which had been identified by the survey working group: local after-school hobby clubs; local after-school sports clubs; local youth clubs attended by hearing young people; uniformed youth groups and local sports clubs. Two options related to activities and clubs designed specifically for deaf children and young people: specialist after-school clubs for deaf children/young people and specialist youth clubs for deaf children/young people. Respondents were asked to indicate which activities their children attended, whether there were any difficulties with their participation and whether these difficulties related to deafness. Open comments were invited in order to elicit brief details about any participation difficulties. To aid clarity, the relevant survey question will be referred to as the ‘Activities Question’, the text of which is set out in Appendix 8.

As the activities concerned are most appropriate to school-age children and above, only data relating to the 233 children in this age-range has been explored.

Chart 5.4 shows that the most popular types of activities were sports clubs followed by uniformed groups. A breakdown of the ‘other’ activity category is shown in Appendix 9, where sports is again the most common category, followed by dance.

Chart 5.4: Instances of attendance at structured activities among deaf children of respondents (Group 1; no learning-related difficulties*; school age [n=233])**



* as defined in chart 4.4

** each column represents percentage of total sub-sample; individual children may be represented in more than one column

***children and young people

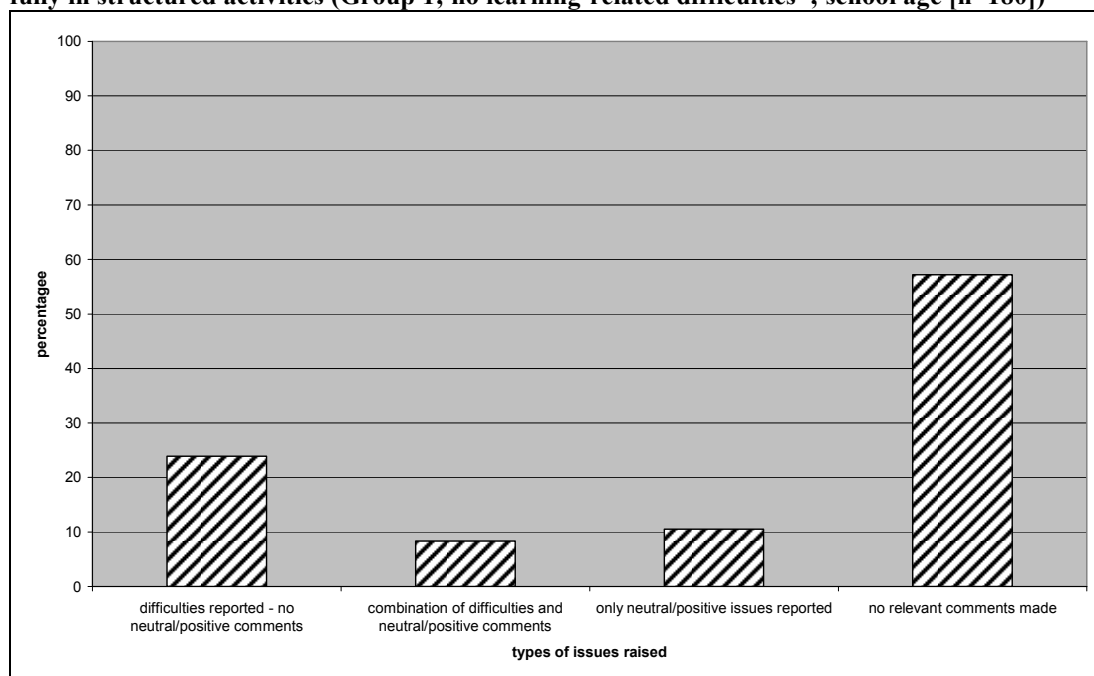
Therefore physical activity was the most popular focus for out of school activity of the Family Survey deaf children population, followed by participation in uniformed groups, such as Scouts, Brownies, Cadets etc. Data relating specifically to sport will be further explored later in this section.

As described, respondents were invited to add brief explanatory comments about any difficulties relating to each activity and in relation to participation in activities more generally. As with the qualitative data on friendships, these comments were coded inductively, resulting in 15 categories, 10 of which describe specific types of linguistic access problem which prevented full participation in activities and the remaining 5 relating to more neutral or positive issues. The categories and examples of comments relating to each one are listed in Appendix 10:

For each child, all comments relating to activities were coded separately and new variables were created in order to analyse results at activity level, child level, and by instance of type of difficulty. There is inevitably some degree of overlap between the categories but, the resulting data illuminates the main kinds of issues which were raised by parents without specific prompt, which, it is argued, has value in itself.

The majority of respondents who reported that their child participated in activities reported no deafness-related problems. However, chart 5.5 shows that 24% (43) of this sub-group of 180 cases reported at least one category of difficulty relating to deafness which prevented their child's full inclusion in activities. An extra 8% (15) additionally reported at least one difficulty plus some kind of neutral or positive issue (categories 11-15). Thus, almost a third of these children and young people had some degree of linguistic/communication access barrier to inclusion in structured activities outside of school. Of the remaining two thirds who did not report difficulties, 19 respondents (11% of total) volunteered at least one neutral or positive comment.

Chart 5.5: Presence of difficulties preventing deaf children of respondents from participating fully in structured activities (Group 1; no learning-related difficulties*; school age [n=180])**



*as defined in chart 4.4

**includes only those who were reported as participating regularly in activities

Almost half (33) of the 72 respondents who reported difficulties noted more than one category of difficulty. The wide range of different permutations precludes clear presentation of the detail of this, and so this has been addressed in two ways: instances of types of difficulty were totalled, to give a clearer picture of issues most commonly raised and, secondly, categories were also conflated to enable breakdown at individual case level by independent variable, such as hearing loss level.

It should be noted that all except two reports of difficulty relate to local mainstream activities. Relatively few children attended the two specified types of structured activity aimed at deaf children and young people, and their situations will be dealt with separately, later in the section.

Chart 5.6 shows the total picture regarding instances of types of difficulty experienced by the deaf children and young people which were reported as preventing participation in mainstream structured activities. As can be seen, ‘missed information/misunderstandings’ is the most commonly raised issue, followed by confidence/anxiety issues and general communication problems. Comments typifying these three categories are as follows:

‘Misunderstands given instructions. Gets frustrated and annoyed with herself or person in charge.’ [category 2]
(primary school age; moderate hearing loss)

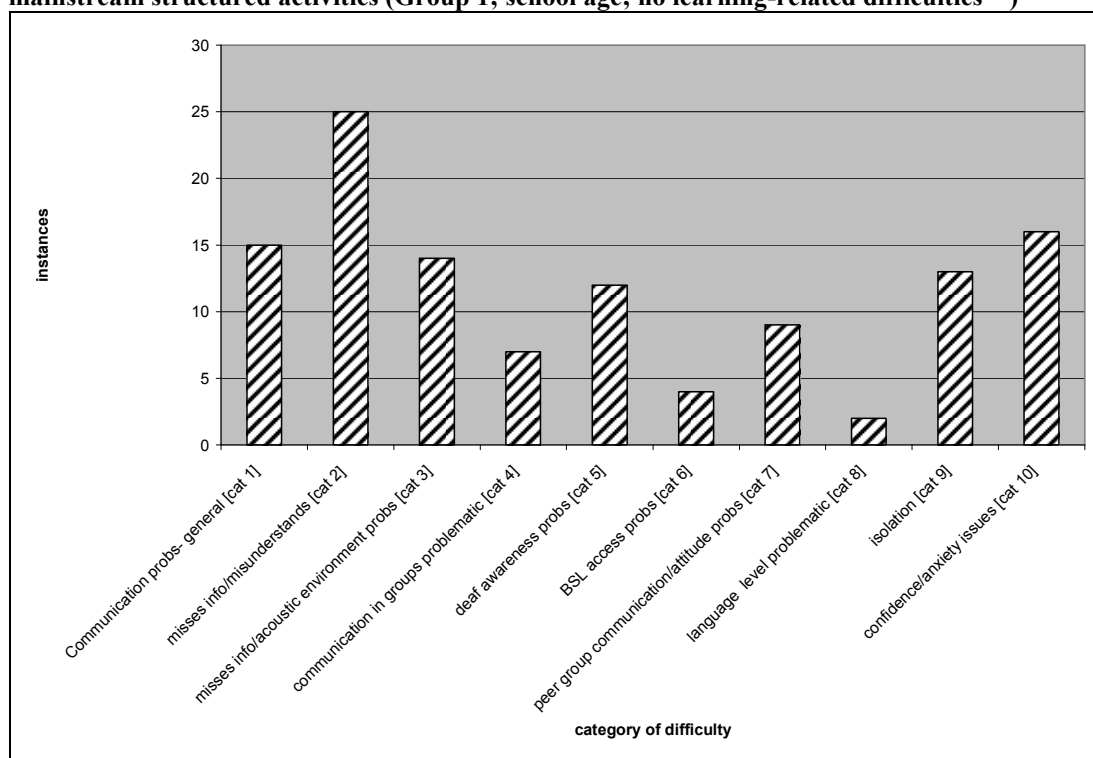
‘Anxiety about being different and possibly not being able to communicate.’ [category 10]
(primary school age; cochlear implant)

‘Communication is always a problem, as are other children’s attitude to deafness.’ [category 1]
(primary school age; severe hearing loss)

Problems relating to acoustic environment tended to be relating to acoustically hostile environments such as cavernous halls, swimming pools or outside:

‘Obviously X has to remove hearing aids and with all the noise and echoes it is hard to hear the teacher’
(primary school age; moderate hearing loss)

Chart 5.6: Instances* of types of difficulty which prevent deaf children participating fully in mainstream structured activities (Group 1; school age; no learning-related difficulties)**



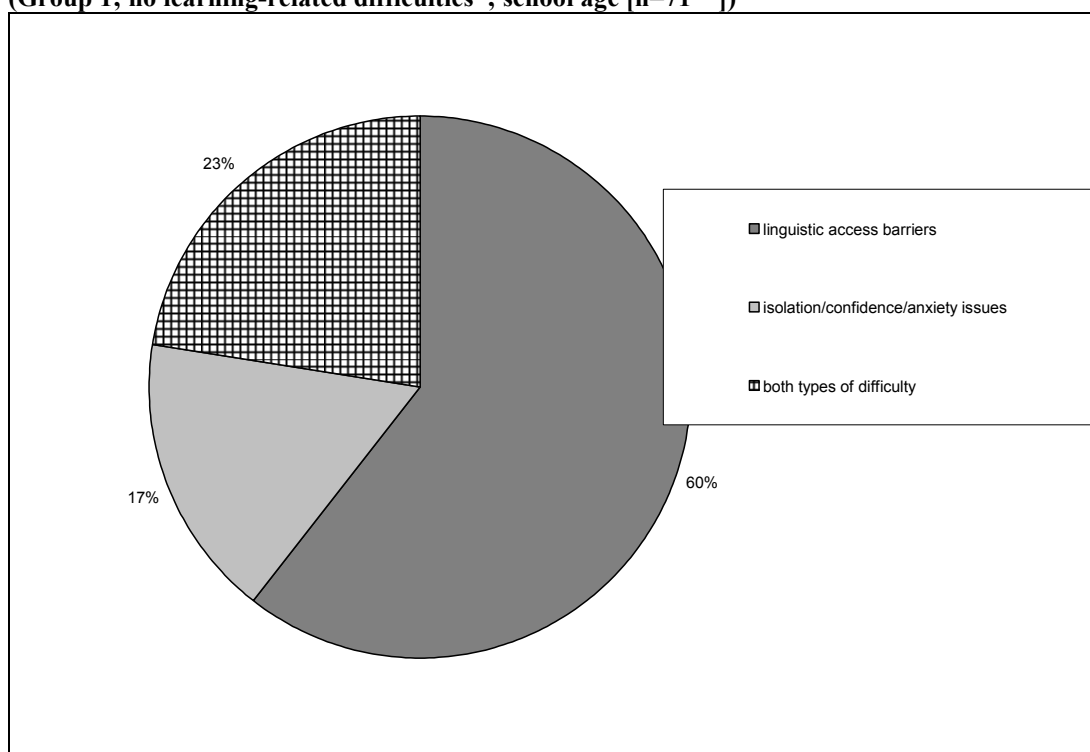
* each column represents the number of children about whom this specific type of difficulty was raised

** as defined in chart 4.4

Categories were conflated as the clearest way of representing optimal detail at individual child level. Three merged categories were constructed: ‘linguistic access barriers’; ‘isolation/confidence/anxiety problems’ and ‘both types of problem’ (at least one from each type). It should be noted here that, in addition to caution over the low numbers (particularly in the mildest hearing loss group) and overlap between categories, an instance of isolation, confidence or anxiety can be an outcome of difficulties experienced rather than a cause of difficulty, per se. As respondents were only asked to provide detail on the type of difficulty experienced, it may have been that some of the target group of deaf children were experiencing these types of psycho-social impacts of linguistic access barriers, but that their respondent parents may not have noted this in their survey response. In other words it is conceivable that

there is some under-reporting of psycho-social difficulties which may have resulted from the difficulties stated in at least one of the linguistic access categories. Bearing this in mind, chart 5.7 shows that 83% of the 71 children experiencing inclusion difficulties in mainstream activities were facing some kind of linguistic access barrier to participation, and 40% were reported as experiencing isolation and/or confidence/anxiety issues which hindered inclusion.

Chart 5.7: Types of difficulty preventing full participation in mainstream structured activities (Group 1; no learning-related difficulties*; school age [n=71])**



*as defined in chart 4.4

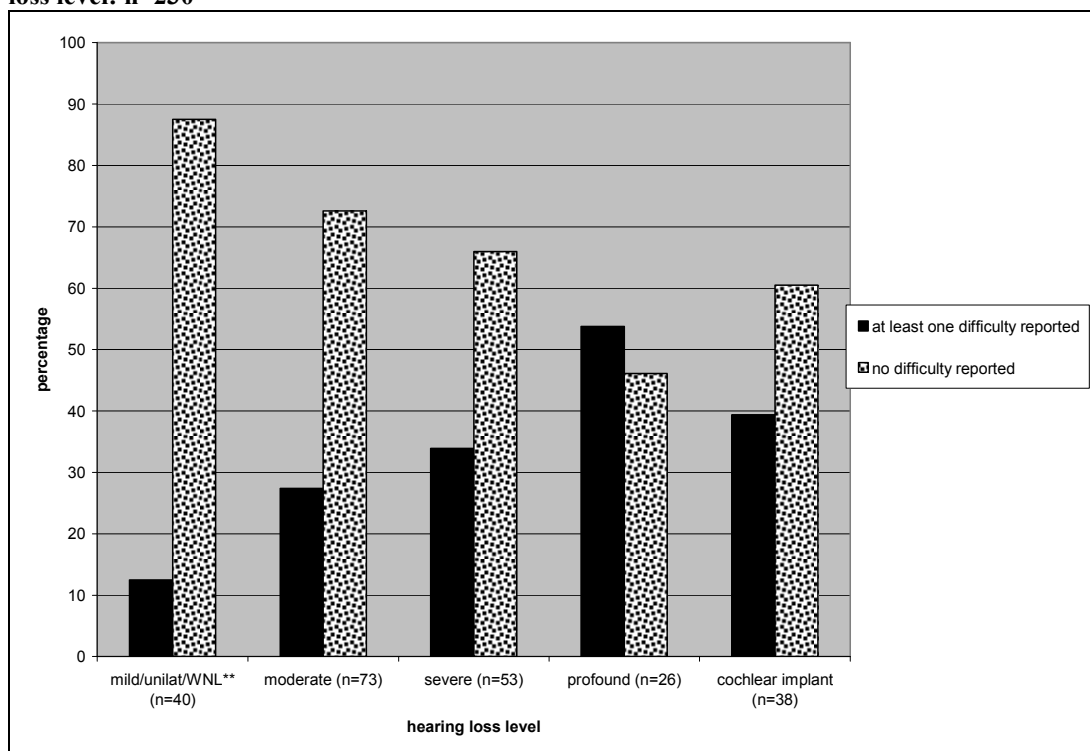
**total represents the number who made a comment about type of difficulty

The data was analysed in relation to hearing loss level of child; first language of child; household social class; hearing status of parents and school level. The data on school level was particularly inconclusive due to the low number of comments made in relation to secondary pupils, and so has not been detailed here. As with other data, it should be noted that the other subgroups are particularly small in number, thus restricting generalisability.

Hearing loss level

The proportion of children with reported difficulties in all activities (including specialist groups for deaf children and young people) in each hearing loss level banding rises with degree of hearing loss, the situation of cochlear implanted children lying in between those of profoundly and severely deaf groups (chart 5.8).

Chart 5.8: Presence of difficulties preventing deaf children of respondents from participating fully in structured activities (Group 1; no learning-related difficulties*; school age), by hearing loss level: n=230***



* as defined in chart 4.4

**within normal limits

*** total no. cases where relevant information was provided

Apart from this indication that hearing loss level is likely to be significant, it is clear that there is diversity in experience across all hearing loss bandings. For each hearing loss band, instances of types of difficulty preventing full participation in mainstream activities were explored (Appendix 11). Little can be read into the proportion relating to those with mild loss, as there were only 6 cases in this group.

As might be now expected, the variation across all hearing loss bands is striking. One perhaps surprising detail is that missing and misunderstanding information was more commonly reported in relation to those with moderate and

severe losses compared to those with profound losses or cochlear implants. Examples of comments in this category among mild, moderate and severe groups are as follows;

‘She has some difficulty following verbal instructions’
(primary school age; mild hearing loss)

‘Swimming lessons are problems as he cannot wear aids and cannot hear instructor’
(primary school age; moderate hearing loss)

‘Little bit embarrassed having to say pardon and missing bits of conversation and not knowing what going on.’
(secondary school age: severe hearing loss)

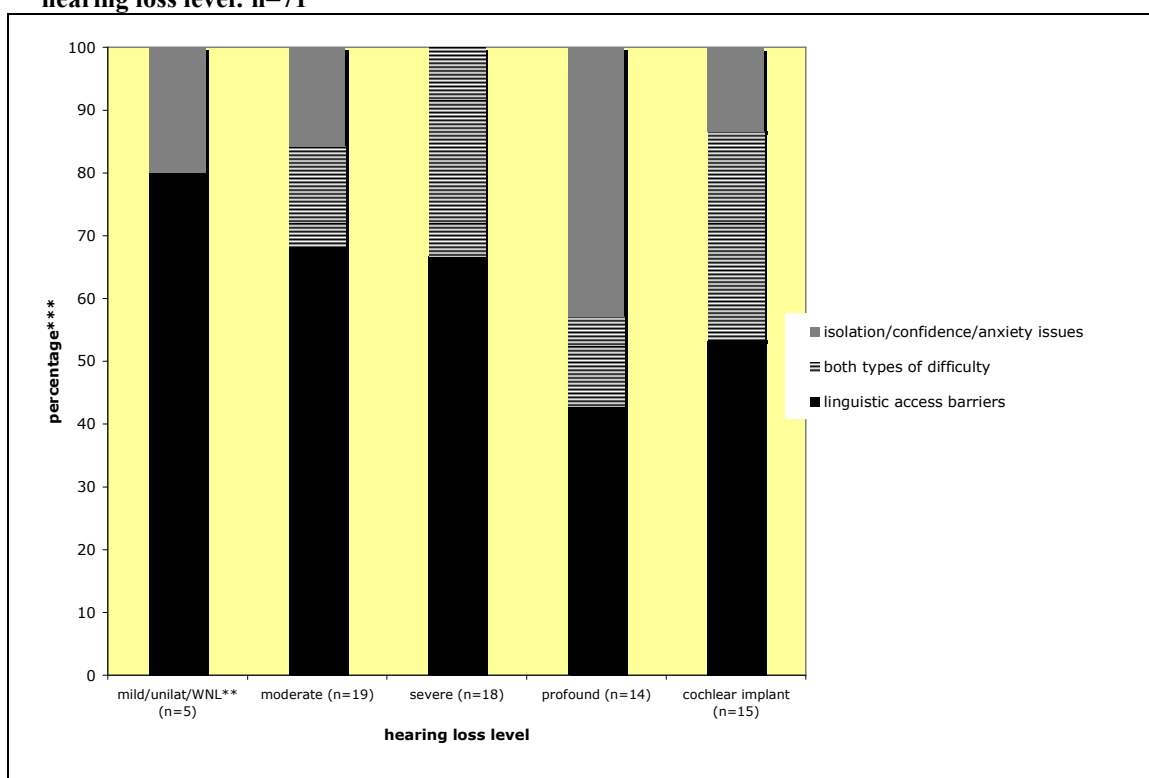
More to be expected is the relatively low level of reports about acoustic environment difficulties among the profoundly deaf group (only one instance) compared to those with moderate and severe losses and those with cochlear implants, as it is least likely that profoundly deaf children will use sound discrimination to access information.

Finally, confidence and anxiety issues featured relatively strongly among comments about profoundly deaf children:

‘Sometimes worries about social interaction and worried about not being able to hear.’
(secondary school age: profound hearing loss)

When the data of those with difficulties is analysed at child level, using the three conflated categories, the relatively high level of psycho-social issues foregrounded by parents of those in the profoundly deaf group is again evident. The chart also shows that, for other groups, linguistic access barriers were the most prevalent types of difficulty raised. Those who were severely deaf and those with cochlear implants had relatively high proportions of reports of both linguistic access and psycho-social issues.

Chart 5.9: Types of difficulties preventing deaf children of respondents from participating fully in structured mainstream activities (Group 1; no learning-related difficulties*; school age), by hearing loss level: n=71****



* as defined in chart 4.4

**within normal limits

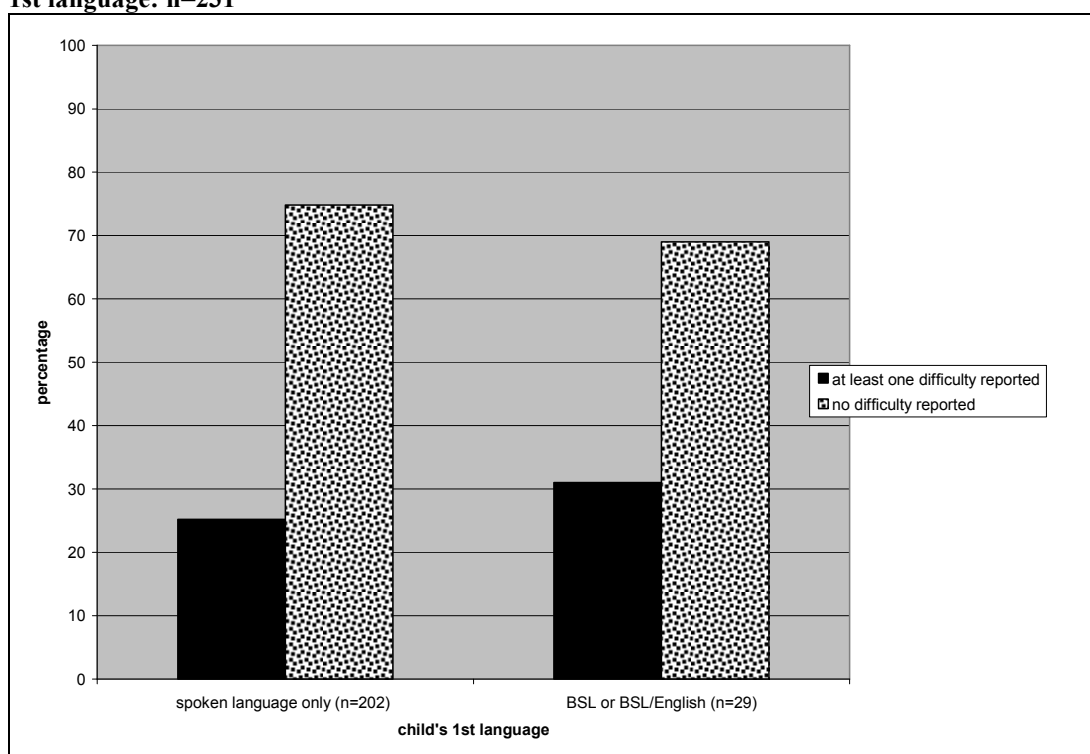
***percentages are calculated for each hearing loss band separately

**** total represents the number who made a comment about type of difficulty

Child's 1st language

Categories of data on first language of child were conflated due to very low numbers with at least one spoken language(s) other than English. Chart 5.10 shows that a slightly higher percentage of those with BSL or BSL/English were reported as having at least one type of difficulty.

Chart 5.10: Presence of difficulties preventing deaf children of respondents from participating fully in structured activities (Group 1; no learning-related difficulties*; school-age) by child's 1st language: n=231**

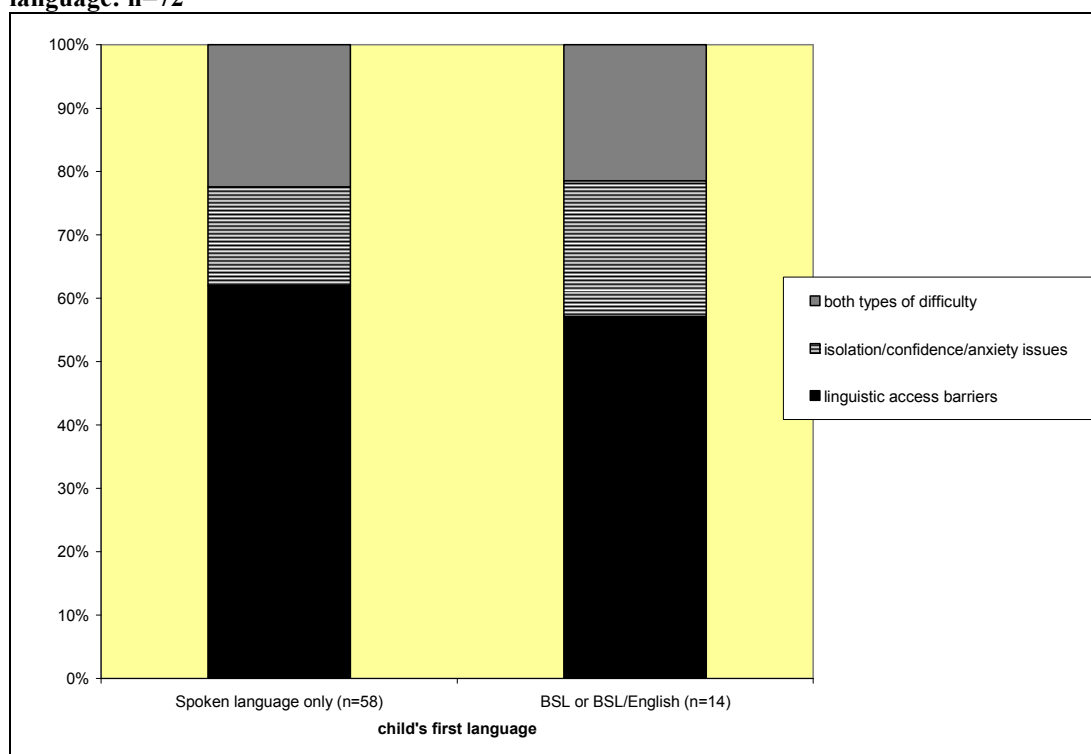


* as defined in chart 4.4

** total no. cases where relevant information was provided

Seventy two respondents provided details of the difficulties experienced, as depicted in chart 5.11. A slightly higher proportion of those with BSL as a first language were reported as having psycho-social issues, but the small numbers involved and the variation amongst comments preclude conclusive comment. Only a small proportion of these comments specifically related to access through sign language. As is mentioned elsewhere, it is likely that some of the comments which allude to general communication apply to BSL access.

Chart 5.11: Types of difficulties preventing deaf children of respondents from participating fully in structured activities (Group 1; no learning-related difficulties*; school-age) by child's 1st language: n=72**



* as defined in chart 4.4

** total no. cases where relevant information was provided

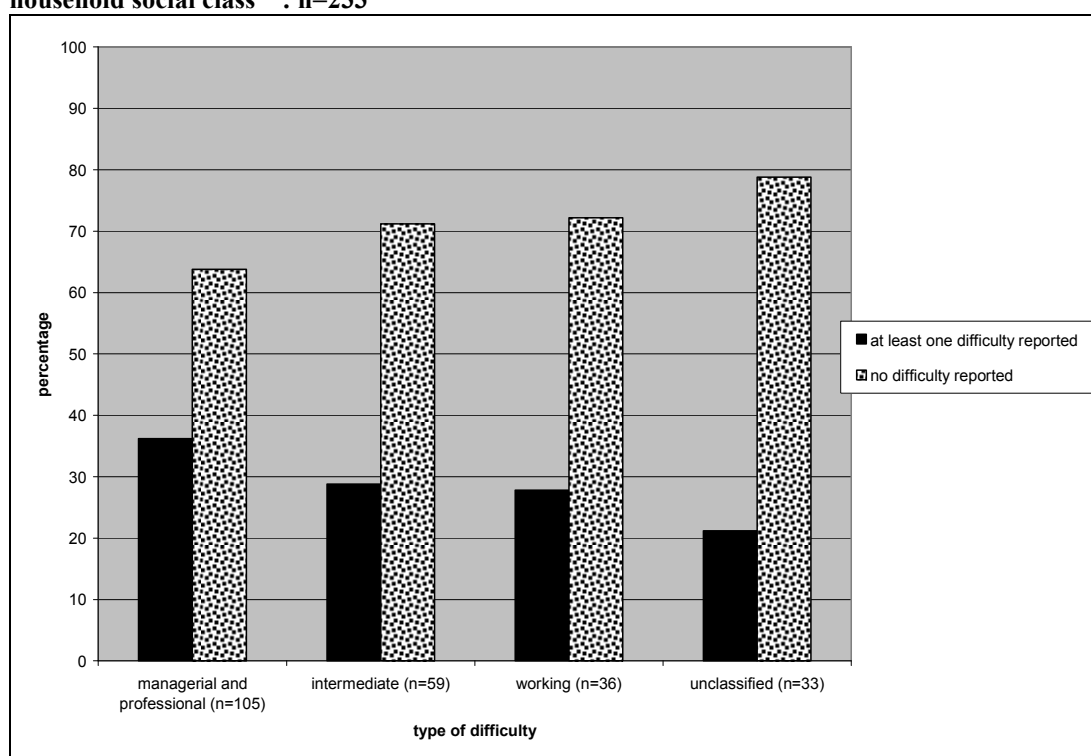
Household social class

As noted in chapter one, there has been shown to be some evidence that socio-economic factors impact on deaf pupil achievement, with indicators of higher social class levels showing a positive effect. Data relating to household social class (as defined by Standard Occupational Categories) were analysed to explore socio-economic influences on difficulties hindering deaf children's inclusion in structured activities. A comment from one respondent clearly made a connection between economic capital and the capacity to improve inclusion opportunities:

‘We can’t see a better way round it than our present solution. We have joined a private gym with small class sizes and more individual attention. It is an expensive solution not available to every family’
(primary school age; moderate hearing loss; ‘managerial and professional’ social class)

This would seem to link to evidence of social class inequalities in terms of participation in sport and leisure activities generally (Green, Smith, & Roberts, 2005). However, the data generally do not show a positive effect of higher social class – if anything the household social class data show the opposite (chart 5.12). Again, size of sub-sample may have a confounding effect: numbers in the intermediate and working class groups are considerably smaller than that in the managerial/professional class group. Also, it may possibly be that higher expectations among higher social class groups could have led to higher levels of expressed concern. More detailed information would be needed before drawing conclusions.

Chart 5.12: Presence of difficulties preventing deaf children of respondents from participating fully in structured activities (Group 1; no learning-related difficulties*; school age), by household social class: n=233**



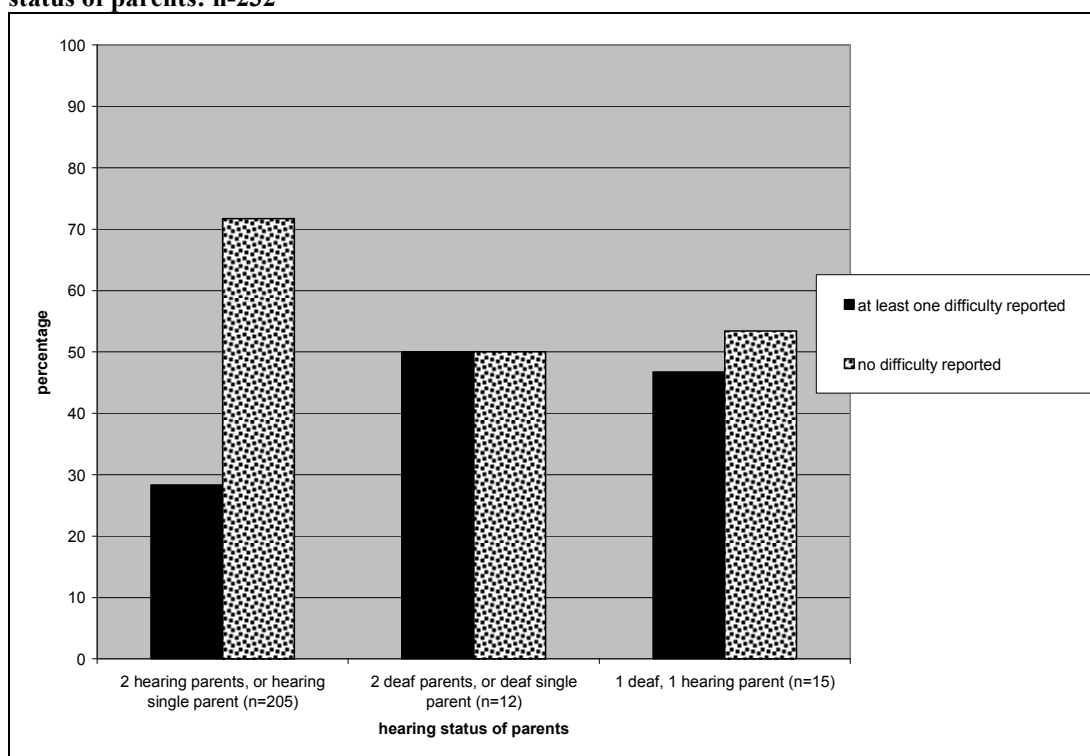
* as defined in chart 4.4

* using Standard Occupational Categories, as described in chapter 3

Hearing status of parents

Although the number of all-deaf-parent households among Family Survey respondents was a small fraction of the number of hearing households, it was highlighted in chapter 4 that not one respondent from all-deaf-parent households reported negative issues regarding communication and discussion at home. However, a different kind of picture emerges when parental hearing status is factored into deaf children's inclusion in mainstream structured activities. Chart 5.13 shows that half of the 12 deaf-parent respondents in this sub-group reported that their child experienced difficulties which prevented their full participation. As before, where there is one deaf and one hearing parent, the situation is in between, although, in this case, their situation is more similar to all-deaf-parent households than to hearing-parent families.

Chart 5.13: Presence of difficulties preventing deaf children of respondents from participating fully in structured activities (Group 1; no learning-related difficulties*; school age), by hearing status of parents: n-232**



*as defined in chart 4.4

**total no. cases where relevant information was provided

The categories of difficulty reported by the six respondents from all-deaf parent households who reported problems, with examples of relevant comments, are set out in table 5.7.

Table 5.7: Examples of comments from 6 deaf parents regarding their deaf children's difficulties with participation in structured activities

| Category of difficulty | Instances | Example of comment [multiple categories in brackets] |
|--|-----------|---|
| BSL access problems [cat 6] | 1 | 'Communication of course – no-one signs' |
| Deaf awareness [cat 5] | 1 | 'No-one is deaf aware' |
| Communication –general [cat 1] | 4 | 'Hard for him to communicate with hearing children and people and feels isolated' [cats 1, 9] |
| Isolation [cat 9] | 3 | 'Hard for him to communicate, tends to be isolated' [cats 1,9] |
| Peer group communication/attitudes problematic [cat 7] | 2 | 'Communication is always a problem, as are other children's attitudes to deafness' [cats 1,7] |
| Missed info/misunderstandings | 1 | 'Children tend to ignore deaf child, felt left out and couldn't follow what it is about' [cats 7, 3, 2] |

General communication problems and isolation were the main issues raised by parents. It might have been speculated that a BSL-immersion situation would have existed for the children in all-deaf-parent households, and that this could have made it more likely that they would experience barriers in the spoken English environments of mainstream structured activities. However, table 5.8 shows that, although most deaf children of these respondents were reported to have BSL as first language, usually alongside English, only one all-deaf-parent household respondent reported that they used BSL monolingually at home. Therefore, without further information to enable exploration of this, it is not possible to make connections between language within the families and the presence or absence of barriers to inclusion in activities.

Table 5.8 First language(s) and home language(s) of deaf children of deaf parents (Group 1; school age; no learning-related difficulties*)

| Participation difficulties | Child's 1st language | Main lang(s) at home |
|-----------------------------------|--|-----------------------------|
| yes | English and BSL | English/sign supported Eng |
| yes | English and BSL | English/sign supported Eng |
| yes | English and BSL | English/sign supported Eng |
| yes | BSL | BSL |
| yes | English and BSL | English and BSL |
| yes | English and BSL | English and BSL |
| no response | English and BSL | no response |
| no response | English and BSL | no response |
| no response | English | English |
| no response | English | English |
| no response | English and BSL | English and BSL |
| no response | BSL | English and BSL |

* as defined in chart 4.4

The size of the group of deaf parents in itself precludes generalisation about the effect of hearing status per se. Also various characteristics of the six cases with difficulties make it more likely that the children/young people would experience problems. For example: four out of the 6 were profoundly deaf (4), and the other two severely deaf – the two categories of hearing loss level most likely to be reported as experiencing problems. Secondly, all problems related to participation in activities where most of the comments about problems are clustered: sports and uniformed groups.

What can be said is that, although there was consistency in reports of high quality of communication at home among all-deaf households, this was not the case in relation to reports about barriers to participation in mainstream activities outside of school.

Interestingly, none of the all-deaf-parent households reported their child's participation in structured activities geared to deaf children.

Specialist groups for deaf children and young people

It was noted in chapter 1 that it is common for deaf children and young people to be attracted to structured activities particularly aimed at deaf individuals, and it has

already been noted that regional and national events run by the NDCS in Scotland were highlighted as important social foci for some children of respondents.

So, it is perhaps not surprising that the vast majority of the 20 respondent parents of deaf children and young people who attended all-deaf activities did not report any difficulties which prevented their children's full participation (five attending after-school clubs for deaf pupils and fifteen attending youth clubs for deaf children/young people). However, there were two children who were reported as having deafness-related difficulties. More detailed vignettes of their situations reveal likely reasons for the difficulties reported, as well as complexities of their individual situations.

Both children were primary school age and had moderate levels of hearing loss. As mentioned in chapter 1, a recent UK survey reported that the extent to which deaf children preferred deaf-only social groups was proportionate to their level of hearing loss and their level of usage of British Sign Language (NDCS, 2008).

In fact, exploration of data on the specialist after-school club and youth group revealed that all other attendees had severe or profound losses or had cochlear implants. Furthermore, although one of the two children was reported to use some BSL in the family, as with some children noted, above, in the 'friendships' section, the respondent (hearing mother) indicated that it was her child's restricted ability in using sign language which made it hard for him to integrate into the deaf youth group. This suggests that, in this case, the youth group may have been a fast-paced BSL environment:

'Finds it hard being with other deaf children as he does not sign as good.'

This 'falling between two worlds' situation resonates with examples noted in relation to friendships, but there are particular complexities in this situation, as the father was reported as being deaf and using some BSL with his son – something

which one otherwise may have thought made it likely that the child would be fully sign bilingual.

In the other case, relating to attendance at a specialist after-school group, it is possible that a fast-paced signing environment may also be an issue – but not necessarily. Here the six-year-old deaf child's first language was a spoken language other than English, which was used with her by all members of the family; some family members were also reported as using spoken English (no usage of manual coded English or BSL). This bilingual spoken language situation thus added another type and level of complication. The respondent's explanatory comment about difficulties accessing the group was, in fact, only one word: 'talking'. It is clear, then, that talking was a barrier but, in the circumstances, there are a number of possibilities of what this could mean. For example, the respondent could have been referring to the child's own level of spoken English, or the fact that she talked rather than signed in a signing environment.

Therefore, while the two children's lesser level of deafness and their lack of, or limited, usage of BSL, may have been significant influences on the difficulties reported in the survey, key data on their individual situations raise as many questions as they answer.

One further issue was raised in the 'general comments' section by the parent of a profoundly deaf child who attended a school for deaf children but who did not attend a specialist deaf group outside of school hours. The quote indicates the fact that (as may also relate to the second of the two vignettes, above) conflicting cultural/religious pressures can add to the complexity of individual situations:

'Mum wants children to be in a safe environment and one that is compatible with their cultural and religious background. Not too keen on the deaf club.'
(primary school level' profoundly deaf)

Sports activities

Previous research has indicated that sport can have special significance for deaf children, because of the potential for excelling on an equal footing with hearing children, as detailed in chapter 1. However, evidence has also been cited of communication problems restricting the participation of some deaf young people to ‘visitorship’ rather than ‘membership’ level.

As was demonstrated earlier in this section, sport was the most popular form of structured activity experienced by the children of respondents. There was some evidence of sports as a means of enhancing social capital:

‘I do feel on the whole quite positive about my son’s achievements...particularly in sports. Without this I would be more concerned about his social interaction’
(secondary school level; severe hearing loss)

Just over a fifth (21%) of those attending after-school or local sports clubs were reported as having deafness-related difficulties. However, many others reported or implied sports attendance under ‘other activities’ or as part of a general comment at the end of the Activities Question and therefore it is difficult to calculate an exact percentage of difficulties which relate to such physical activity. Taking all this into account, it was noticeable that a large proportion of comments relating to activities difficulties were concerned with participation in sporting activities of various kinds. While these comments were spread throughout all of the linguistic access and psycho-social categories of coding, some specific themes emerged which are worthy of exploration.

Missing or misunderstanding information was a common problem among reports of difficulties. Among those relating to sports, inability to follow instructions was a prevalent problem, and this was the case across hearing loss levels, and whatever linguistic strategy was used to access information.

The nature of some popular sports require removal of personal amplification equipment such as hearing aids and cochlear implant speech processors, either

because of the likelihood of damage through water immersion when swimming or due to the roughness of physical contact (eg karate or rugby). Thus, those of the sample who normally accessed information via amplified speech could be at a disadvantage:

‘Swimming lessons are a problem as cannot wear hearing aids and cannot hear the instructor.’
(primary school level; moderate hearing loss)

‘X swims and takes part in galas – there are often problems with starting races. She requires visual clues’
(primary school level; cochlear implant)

These problems were exacerbated, for those who use audition, by the fact that locations of activities were often in the acoustically-hostile environments of cavernous halls and pools, prone to echo, or were held in noisy outdoor situations:

‘Has difficulty [with swimming] in a large, noisy class following instructions.’
(primary school level; severe hearing loss)

‘Rugby, trains and plays outside. Difficult to hear.’
(primary school level; severe hearing loss)

For those who used lip-reading as a strategy, it is not hard to imagine that this could be problematic where lip-reading conditions were not ideal:

‘Swimming lessons given by pool staff who stand way above the children’s heads and shout instructions while walking away.’
(primary school level; moderate hearing loss)

‘X’s hearing aids removed for swimming so lipreading vital and always has to explain to other people re can’t hear them properly.’
(secondary school level; moderate hearing loss)

Where a child's first or preferred language was BSL, there were some reports of lack of staff able to use BSL and/or lack of BSL/English interpreter:

‘Wish people [at swimming lessons] were more deaf aware or could sign.’
(primary school level; profound hearing loss)

Many sports require fast-paced group communication, particularly team games; as might be expected, this was shown to be problematic for many:

‘Team games [are problematic] as instructions and understanding of rules is difficult. Child is outstanding middle distance runner but games elude her.’
(primary school level; mild hearing loss)

‘Sometimes [sport] too noisy for her – likes more one to one than in a group.’
(primary school age; moderate hearing loss)

As already noted, above, one parent had decided to join a private gym specifically so that her son could experience smaller groups and more individual attention.

Lack of ‘deaf awareness’ among leaders and instructors was directly described or indirectly implied by many of the comments. Some examples describe clearly discriminatory behaviour:

‘Noise and echo of pool has meant X can’t hear properly and learns (good or bad) via copying. One instructor told him if he didn’t listen better he would throw him out of class!’
(primary school level; severe hearing loss)

‘Football team, skilful player but rarely gets a game, coach cannot communicate while playing. School hockey team, misses meeting as not told they are being held and is therefore not allowed to play in matches at other schools.’
(secondary school level; severe hearing loss)

As with other types of activity, the symbiotic relationship between linguistic access barriers and psycho-social barriers was apparent:

‘X can feel socially isolated if people exclude her [at swimming] because she cannot always hear what they say.
(secondary school level; moderate hearing loss)

‘Hard for him to communicate [during football], tends to be isolated.’
(secondary school level; severe hearing loss)

Research literature was discussed in chapter 1 which indicated that fathers sometimes take on the role of leader within a sport in order to facilitate their child’s inclusion. There was one specific instance of this, but also a number of reports of either parent taking on roles of assistant instructor or interpreter:

‘X attends football training both at school and out local sports centre. However, my husband is actively involved in the school football and stays with X at the local sports centre. This is because of X’s communication difficulties and to ensure that if he gets hurt around the area of his cochlear implant that there is someone who knows what to do.’
(primary school level; cochlear implant)

‘Skis – junior training. Needs one of his parents to ski with him to assist with communication.’
(secondary school level; cochlear implant)

‘[swimming] limited to when mum can be on hand to convey what is required.’
(primary school level; moderate hearing loss)

It was noted in chapter 1 that taking on such roles could potentially be problematic if there was a consequent sense of over-protection. This will be addressed later on in this chapter.

It is likely that these kinds of roles would be more difficult for deaf parents to fulfil and, indeed, there were no reports of deaf parents becoming involved in activities in order to facilitate communication.

As noted at the start of this section, there were a number of positive comments, made by respondents about participation in activities generally, and the last part of this section will briefly address these.

Positive comments

In the discussion of relevant research literature in chapter 1 it was pointed out that some deaf young people can resiliently develop their own inclusion strategies to counteract barriers. Bearing in mind Young et al.'s (2008) warning about the need to take into account all levels of the context of the child and their situation, in identifying 'resilience', there was some evidence of such individual coping among comments made. However, comments had to be brief because of limited space, so there is little detail as to what made the difference:

'...Sometimes I worry that they will bypass him [because he doesn't hear instructions] but he is learning and holding his own].
(primary school level; moderate hearing loss)

'X is well known and has confidence to join groups – he can explain how he lipreads'
(secondary school level; severe hearing loss)

As shown at the beginning of this section, 12% (31) of the 233 respondents in the sub-sample made only positive or neutral comments about their child's participation. Some reflected the impact of good practice on the part of adult leaders:

'...Guides have been very good making a real effort to be inclusive.'
(secondary school level; mild hearing loss)

‘Brownies are fantastic with X. They even had a social worker from deaf visit to explain what it is like for deaf people.’
(primary school level; moderate hearing loss)

Structured activities: summary comment

In summary, it has been demonstrated that almost a third of those Group 1, school-age children/young people who had no learning disabilities were reported to be experiencing deafness-related difficulties which prevented full participation in structured activities outside of school. Nearly all of these difficulties related to local, mainstream groups and clubs. A correlation was found between hearing loss level and the presence of difficulties. No conclusive comments could be made about findings relating to household social class, hearing status of parents, or first language of child, due to a number of confounding factors. Bearing this in mind, a number of interesting patterns emerged. For example, those in the higher social class bracket reported most difficulties, despite other evidence that higher income increased opportunities for accessible provision; a connection between higher occupational status and higher expectations was mooted. Also, as a contrast to the situation regarding family communication, children in all-deaf-parent households were at least as likely to be reported as having ‘visitorship’-type experiences as deaf children in all-hearing-parent families. To a lesser extent, those with BSL as a first language were more likely to be reported as having difficulties compared to those with spoken language only.

The most common type of problems faced were those within the broad category of linguistic access barriers – missed information and misunderstandings being most frequently reported. Other commonly reported barriers include: general communication problems; missed information due to noisy environments; deaf awareness problems and problems relating to peer group communication and attitudes. Psycho-social issues around isolation, lack of confidence and anxiety were reported by more than a third of the group, but were particularly fore-grounded in comments relating to profoundly deaf children and young people, and, less markedly, among those with BSL as a first language.

A parent from Eriks-Brophy's (2007) research was quoted, in chapter 1, as saying that sport was 'a niche that gives some credibility' to his deaf child's status within his peer group. This is in the context of the significant part that families play in the nurturing of *all* children's sports talent (Kay, 2000). Given the potential impact on self esteem, it is a matter of concern that there were so many reports of difficulties within this Family Survey sub-sample. Although the majority of those attending sport were not reported to have difficulties in participation, linguistic access and/or psycho-social obstacles were described for a substantial proportion. Whatever the hearing loss level or language (spoken or sign) of the deaf child or young person, or the linguistic strategy for accessing information, barriers were evident which were preventing exploitation of a potential route for enhanced self-worth.

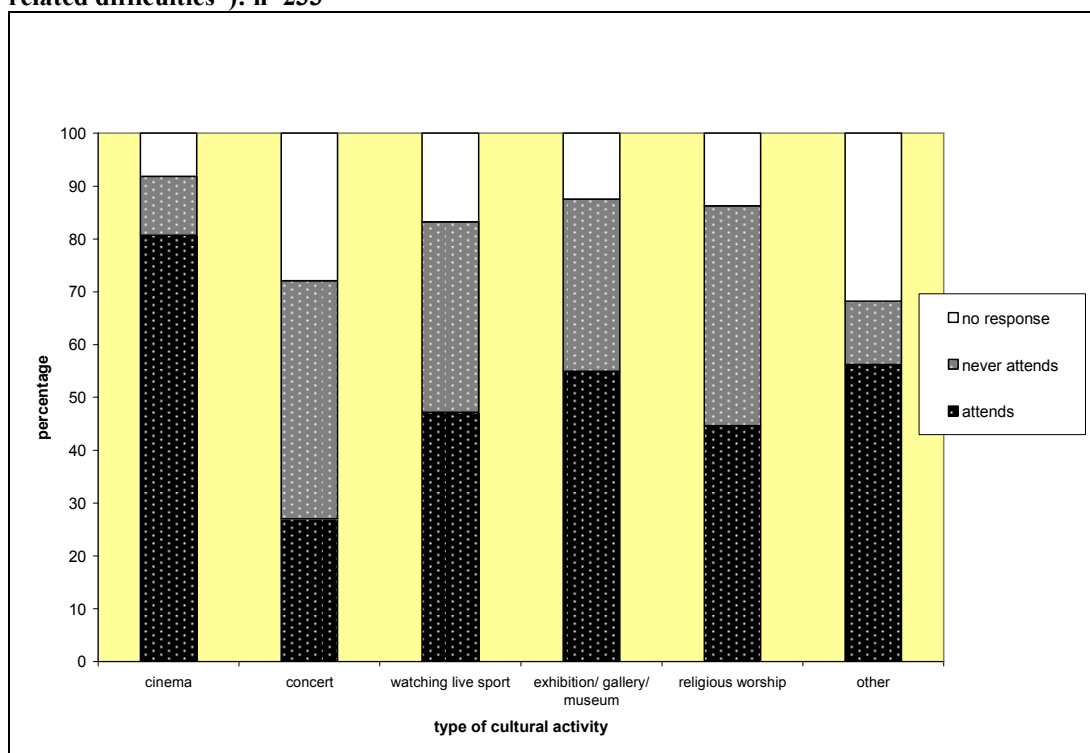
Overall, although two thirds of respondents within this sub-group did not report inclusion problems in mainstream situations (and, as noted, some volunteered positive experiences), there was considerable diversity among the characteristics of the third who did report difficulties. The nature of the difficulties indicate that many of the children concerned were likely to have been experiencing 'visitorship' rather than 'membership' of activity groups. This mostly related to mainstream situations, but also applied to activities aimed at deaf individuals, in the case of two moderately deaf children.

Participation in cultural activities

A further question elicited information on attendance at cultural events and activities: concerts, exhibitions/art galleries/museums; places of worship and 'other activities of importance'; it will be referred to here as the 'Cultural Activities Question' (see appendix 12 for text). Again only data relating to the 233 cases in the sub-sample of Group 1 children of school age with no learning disabilities was included.

Chart 5.14 illustrates the fact that the most popular form of cultural activity was cinema, with by far the highest level of attendance and the smallest proportion of ‘never attends’ responses. At the other extreme, only just over a quarter of the sub-sample attended concerts and almost a half were said to never attend them.

Chart 5.14: Attendance of deaf children at cultural activities (Group 1; school age; no learning-related difficulties*): n=233**



* as defined in chart 4.4

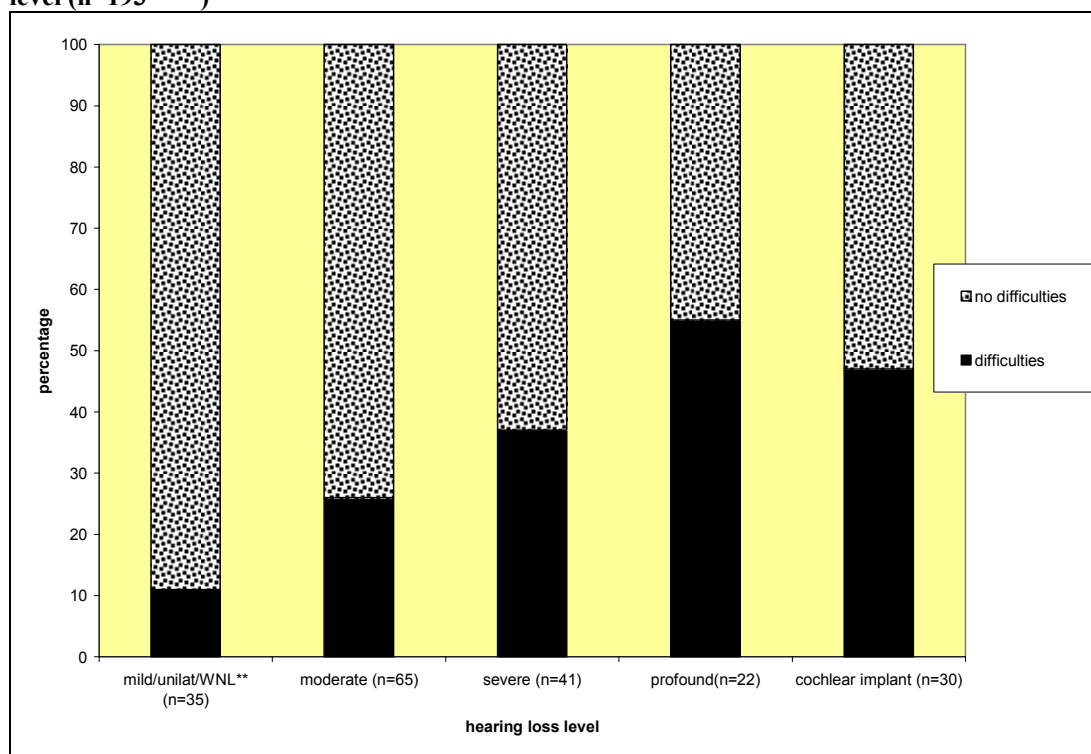
** each column represents the breakdown of responses for all cases in this sub-sample

It was hypothesised in chapter 1 that language and communication restrictions are likely to impact on a deaf child’s accumulation of cultural capital as well as social capital, in the context of the dominant values which define ‘culture’. Assuming that such values are rooted in a socio-economic hierarchy, the data was analysed by the ‘household social class’ variable, as defined in chapter 3. Results demonstrate that, other than watching live sport, children in the highest socio-economic class band were generally more likely to attend cultural activities, and less likely to ‘never attend’ activities, compared to lower class bands (Appendix 13). However, the margins were very small in some areas and, as with other findings in this chapter, there was wide disparity between the sizes of the groups. Therefore, the most that

can be said is that there may be a slight class bias in findings related to those attending cultural activities, other than fully related to watching live sport.

Eighty three percent (194) of the sub-sample indicated whether or not there were deafness-related difficulties which hindered participation. Almost a third (32% [62]) of these reported difficulties. Break down by level of hearing loss reveals a relationship between hearing loss level and proportion of deaf children with reported difficulties, with profoundly deaf children having the highest proportion at 55% (12). The percentage of cochlear implanted children (47% [14]) was exactly half way between that of severely deaf and profoundly deaf children (chart 5.15).

Chart 5.15: Presence of difficulties relating to deafness preventing deaf children's participation in socio-cultural events (Group 1; school age; no learning-related difficulties*), by hearing loss level (n=193**)**



* as defined in chart 4.4

**within normal limits

*** total no. cases where relevant information was provided

Relatively high proportions of those with BSL or BSL/English as first language(s) (66%[14,]) and of those with deaf parents (83%[8]), were reported as

having difficulties. Contrasting proportions for those with English as first language and those with hearing parents were, respectively, 27% (45) and 29% (50).

Forty five of the 62 respondents who reported difficulties provided explanatory comments, which were inductively themed into 7 categories. Three of the categories relate to problems with specific linguistic access strategies: reading subtitles; using audition via amplification and using BSL. Table 5.9 shows that the majority of instances of difficulties fell into this collective grouping. It should be noted that some respondents reported more than one difficulty per child, but each row represents the number of children reported as experiencing the relevant type of difficulty. Another point of note is that it is likely that 4 out of the 7 comments in the ‘general communication problems’ category related, at least in part, to BSL access (see footnote to table).

Table 5.9 Types of difficulty hindering deaf children’s attendance at cultural activities (Group 1; school age; no learning-related difficulties*)

| Type of difficulty | No. instances of comments | % of total comments |
|----------------------------------|----------------------------------|----------------------------|
| audition issues | 19 | 42% |
| subtitle access | 18 | 40% |
| unable to follow what’s going on | 17 | 38% |
| BSL access | 6 | 13% |
| general communication problems | 7** | 16% |
| safety/dependency issues | 5 | 11% |
| miscellaneous | 6 | 13% |

* as defined in chart 4.4

** 4 of those in the ‘general communication problems’ category had BSL or BSL/English as 1st language(s), and therefore BSL access was likely to be an issue for these 4 children, even though not specified as such

Types of comments were broken down by hearing loss level and by 1st language (Appendix 14). Audition issues were most commonly either related to the lack, or poor quality, of amplification systems, or to excessive background noise. Those with moderate or severe hearing losses, were most likely to experience such problems, and all 19 had English as first language:

‘Most places don’t have the facilities in our area to accommodate deaf people ie loop system etc’
(primary school level; moderate hearing loss; English as first language)

‘Concerts too noisy with hearing aids, not enough places have loop systems.’

(secondary school level; severe hearing loss; English as first language)

Lack of subtitles – particularly in cinemas - was reported across all hearing loss levels, apart from mild, and across all first language groups.

‘Cinema - dislikes the lack of subtitles. If waits till the one day that there are subtitles (20 miles away) everyone has already seen the film.’

(secondary school level; severe hearing loss; English as first language)

Problems relating to BSL access were, unsurprisingly, only reported about children with severe or profound losses, or those with implants. Nearly all comments in this category also indicated lack of subtitles:

‘If a theatre performance is not signed or there are no subtitles on a film, understanding what is happening becomes much more difficult. I have sat beside him and tried to sign for him, it helps but it is far from ideal.’

(secondary school level; cochlear implant; BSL and English as first languages)

As noted above, it is likely that the four parents of BSL-using children who reported general communication problems would have been, at least in part, referring to BSL access within their comments:

‘Communication problems and understanding what it is all about.’

(secondary school level; profoundly deaf; BSL and English as first languages)

Generally having difficulty following what was going on at events was a common theme, which cut across all hearing loss levels and applied to those with both English and BSL/English as first languages. Some parents noted that they were having to take time to provide explanation:

‘Discussion time to explain what has happened within events that they have only partially heard or misunderstood.’
(primary school level; moderate hearing loss; English as first language)

‘Cinema - always asking us for clarifications. Finds church quite difficult but enjoys singing.’
(secondary school level; profound hearing loss; BSL/English as first languages)

The situation of parents putting in specific effort to facilitate their children’s access to knowledge and general participation in activities has already been mentioned earlier in this chapter. This was also a theme among reports about access to cultural events. The following comment illustrates this theme - as well as the fact that children of all hearing loss levels used various permutations of linguistic access strategies to access information – in this case written English and BSL:

‘We always try to go to cinemas showing sub-titles and take X to church service which is signed to ensure he gets “maximum input” to aid his understanding.’
(primary school level; cochlear implant; BSL and English as first languages)

Cultural activities: summary comments

Therefore, in summary, while the majority of respondents reported no deafness-related difficulties, it appears that a sizeable minority were experiencing access barriers to cultural activities – particularly those with greater hearing loss levels. Insufficient subtitling in cinemas was the most common specific issue. This and a general lack of ability to follow what was going on were issues which transcended the effect of hearing loss level. As with social activities, a range of linguistic access strategies were used by children and young people to access information - and the same issues apply, as raised in the previous section, in relation to choice of strategies used.

Relatively high proportions of those with BSL as first language and those with deaf parents were reported as having difficulties, perhaps reflecting the low

availability of BSL interpretation. Some hearing parents took on the role of interpreters and facilitators of information, which may, in some cases, link to the likelihood of a more didactic communication relationship than would be the case with hearing children. However, there was no evidence of deaf parents taking on this communication facilitation role, which is not surprising, as deaf parents are less likely to be in a position to do so.

Some evidence was presented in chapter 1 which indicated that increased likelihood of parental involvement in their deaf children's out-of-school activities could lead to a sense of over-protection. The final section of this chapter links to this situation, in so far as it focuses on the challenges facing parents in facilitating their deaf child's independence during adolescence.

Research Question 3: Using parent reports, how far do deafness-related issues affect the extent to which parents encourage their deaf adolescent children to be independent outside of school?

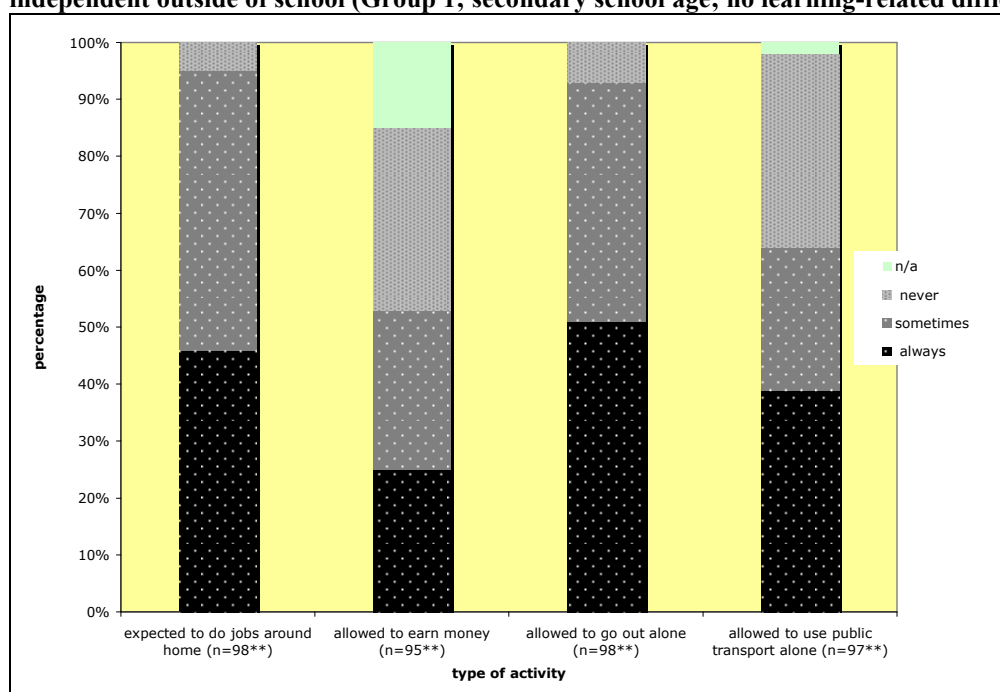
The importance of the development of autonomy and self determination during adolescence, and the difficulties faced by parents in achieving a balance between encouraging independence and protecting their children from harm were discussed in chapter 1. Parental collaborators in the Family Survey design had shared anecdotal evidence which coincided with that described in the relevant literature reviewed – evidence which indicates that parents of deaf children could find it particularly difficult to take the risks involved in allowing their children to develop independence skills in their teenage years. Therefore a question was included which elicited information, using four indicators devised from discussions with parents on the advisory group and key staff in the University of Edinburgh's Centre for Educational Sociology. It will be referred to here as the Independence Question. Respondents were asked to indicate: to what extent they enabled specific

independence-related activities; whether any difficulties relating to deafness caused restrictions and, if so, to provide brief details (see Appendix 15 for text).

As with the exploration of other types of activity already undertaken, analysis was restricted to Group 1 children with no learning disabilities; in this case the group was also limited to children of secondary school age (12 years and above). The resulting sub-sample comprised 103 cases and so limitations to generalisability again apply.

Initial analysis revealed that, out of the four indicators of independence, earning money and travelling independently were the two activities which deaf children in this sub-sample were least likely to be allowed by their parents to do (chart 5.16). No conclusive relationships were evident between proportions of ‘never’ responses and hearing loss level, age, first language, household social class or hearing status of parents. In the latter case, this was largely relating to the fact that there was only one all-deaf household (albeit with two deaf children in this age group).

Chart 5.16: Extent to which deaf children of respondents are allowed by parents to be independent outside of school (Group 1; secondary school age; no learning-related difficulties*)



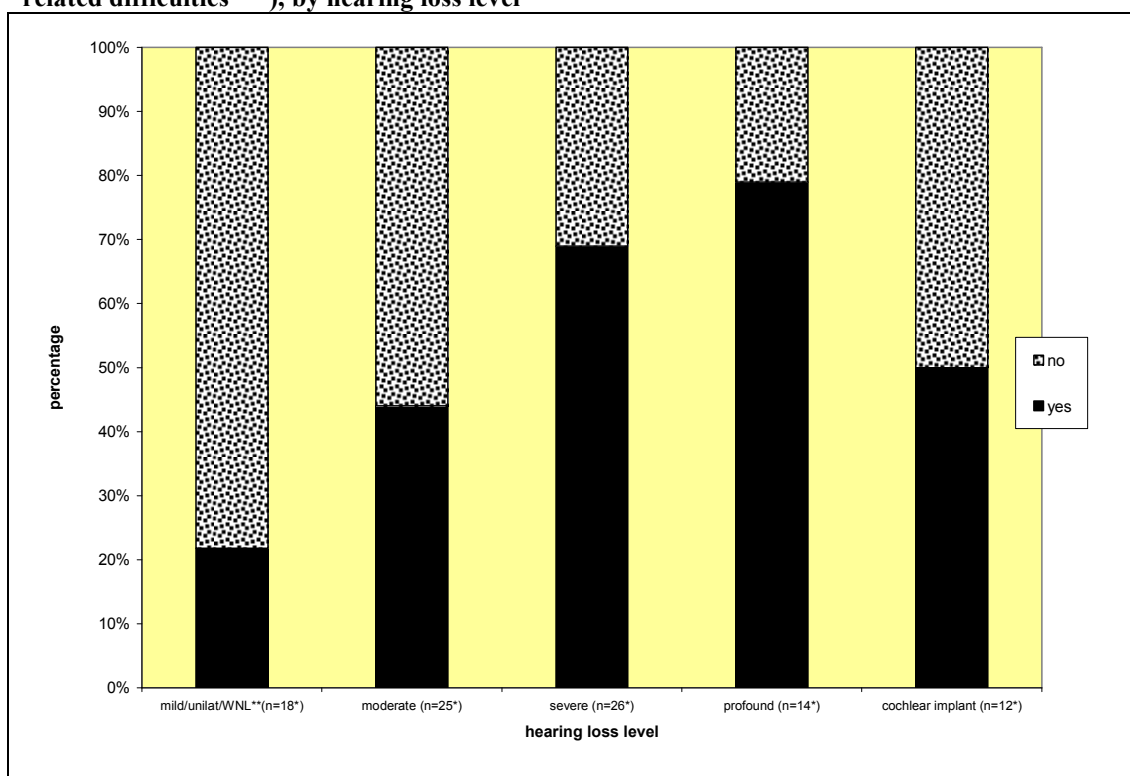
* as defined in chart 4.4

**total of each column represents the number of children about whom information on this issue was provided

50 (49%) of the sub-sample indicated that there were difficulties relating to their child's deafness which prevented them from allowing any of these independence-related activities.

When the data on presence of difficulties was broken down, there were no clear relationships with age or first language. However, there did seem to be a relationship with level of hearing loss, as shown in chart 5.17: unsurprisingly the greater the level of hearing loss, the more likely that difficulties would be reported.

Chart 5.17: Presence of difficulties relating to deafness which restricted respondents' willingness to allow their deaf children to be independent (Group 1; secondary school age; no learning-related difficulties*), by hearing loss level**



* total of each column represents the number about whom hearing loss information was provided

** within normal limits

*** as defined in chart 4.4

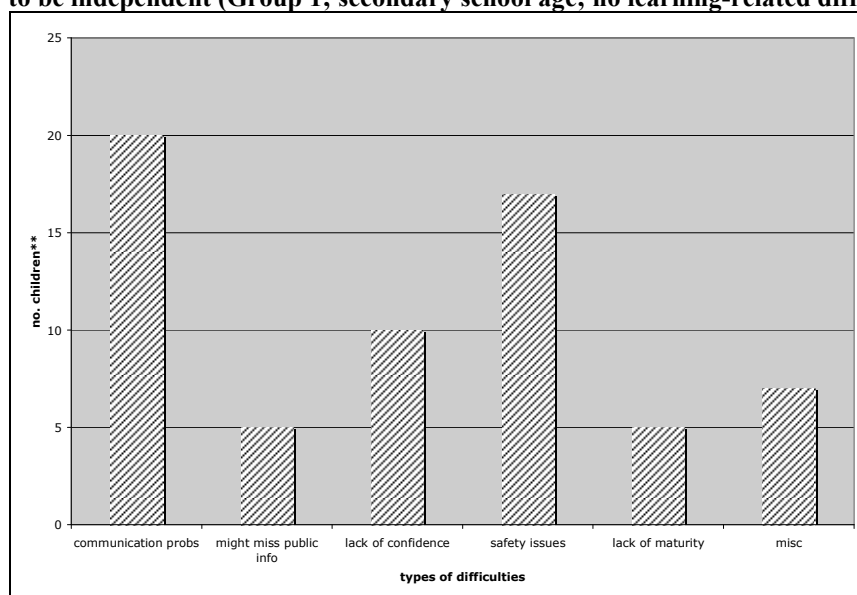
The situation of cochlear implanted children was in between those of moderately deaf and severely deaf children. This may well indicate that the greater access to sound afforded by the implant impacted on the extent to which parents allowed independence, as was suggested by two thirds of respondent parents in

Archbold et al's 2008 study, who reported that their implanted children were as independent as most other children of their age, despite over 80% indicating that their child had been very dependant on them prior to implantation three years previously. . However, there may be some confounding socio-economic effect in this Family Survey sub-sample of implanted children: it transpired that 8 out of 12 were in the highest class and none in working class category. Due to low numbers (and the inconclusive relationship between social class and the independence indicator data), all that can be said is that even more caution is needed in drawing conclusions about the place of implanted children in the pattern which emerged.

Whether or not there is more than a correlation relationship between hearing loss and level of independence encouraged by parents, it is still worthy of mention that even among children with a slight hearing loss, over a fifth were reported as having some level of deafness-related restriction put on their independence - and over 40% of those with moderate loss.

All but 3 of the respondents who reported difficulties provided a brief explanatory comment. Comments were themed inductively as with other similar data described throughout this chapter. Chart 5.18 reveals that the most common types of concerns coincided with those found within the research literature: communication and safety issues. Respondents from all three all-deaf-parent households reported these issues.

Chart 5.18: Types of difficulties limiting parents' willingness to allow their deaf children to be independent (Group 1; secondary school age; no learning-related difficulties*) n=50



* as defined in chart 4.4

** each column represents the number of children about whom a comment was made which noted this type of difficulty

Communication problems were reported throughout all levels of hearing loss and age groups and whether English or BSL was reported as first language:

‘She does not work (eg paper round) I think she could find it hard sometimes to follow instructions. She earns her money at home.’
(mild hearing loss; English first language; aged 13)

‘I’m too nervous to allow him to use public transport in case he cannot interpret what a stranger (bus driver) may have said/asked.’
(moderate hearing loss, English first language; aged 13)

‘Communication with strangers is daunting.’
(severe hearing loss, English first language; aged 13)

‘X cannot communicate very well with people she doesn’t know e.g. on public transport.’
(profound hearing loss; English and BSL; aged 16 years)

‘X finds her deafness- even with her implant - is restricting her understanding of speech from others and her own.’
(cochlear implant; English & BSL; aged 12 years)

Most fears about safety problems were related to traffic/travel problems, tallying with other literature noted in chapter 1, and to vulnerability in relation to potentially predatory strangers:

Could not go to the shops alone or travel on public transport. Too dangerous and not confident enough. We take her in the car.
(severe hearing loss; English first language; aged 16 years)

‘Lack of confidence related to deafness. She doesn’t understand who is good and who is bad - doesn’t understand she shouldn’t go with strangers. She wouldn’t be able to defend herself.
(profound hearing loss; English first language; aged 13 years)

Lack of maturity and lack of confidence and were also common themes:

‘I feel that she lacks maturity and that this could be related to her hearing loss.’
(severe hearing loss; English first language; aged 12 years)

‘X will not go out by himself. We are working towards him going out and building his confidence.’
(profound hearing loss; English first language; aged 15 years)

This last quote was typical of 7 comments which included a positive element to some degree; either, as in this case, suggesting ‘work in progress’ towards fuller independence or indicating that parental concerns about impact of deafness were not actually impeding the development of independence. The following example is the reflection of a parent struggling to suppress the temptation to be overly protective:

‘Slower in gaining confidence/less streetwise than her peers. Has worrying parents - but certainly no major difficulties to prevent her doing all of the above.’
(cochlear implant; English and BSL; aged 12 years)

It was interesting that some of the respondents who had reported that there were difficulties preventing independence had also indicated a lack of imposed parental restriction. Thus there were a number of examples where ‘always’ or

‘sometimes’ responses were ostensibly contradicted by reports of prohibitive difficulties. For example:

‘My son lacks confidence to go on the bus and go to the shops himself. Also, as he prefers his own company out of school, lacks a friend to go with.’

(severely deaf; aged 13; mainstream school; respondent reported that their child was ‘always allowed to travel alone by public transport’)

‘Have concerns about her using public transport because she wouldn’t hear announcements/warnings etc’

(cochlear implant; aged 15; mainstream school; respondent reported that their child was ‘sometimes allowed to travel alone by public transport’)

‘X had a bad experience with a bus driver, so she will not go on a bus by herself’

(profoundly deaf; aged 17; mainstream school; respondent reported that their child was ‘sometimes allowed to travel alone by public transport’)

This suggests that there were likely to have been differences among parents in how they interpreted the question, and that there was a fairly wide range of levels of restriction encompassed within the findings – from complete prevention through varying levels of limitation. It also means that the information presented in chart 5.17 underestimates the extent of restrictions among the sub-sample and so should not be seen in isolation.

Evidence cited in the research literature chapter pointed to a difference between deaf and hearing parents – with deaf parents being more likely to facilitate deaf children’s independence. There was only one all-deaf-parent family in this sub-group, and so their case can only be seen in isolation. However, in fact, the mother reported restrictions in relation to both of her secondary-age deaf children – those relating to the younger one being greater than those imposed by hearing parents on

any of the other 12-year-olds in the sub-sample (ie., never allowed out alone compared to ‘sometimes’ or ‘always’ responses).

As noted in the previous two sections in this chapter, hearing parents can end up accompanying their child to activities in order to fulfil a facilitative role. There were a number of comments which indicated that parental assistance with communication could be double-edged for a child reaching the age when peer group norms dictate demonstration of independence from parents. The following comment was made in relation to the Activities Question and actually referred to a primary school pupil:

‘Brownies are not accessible without signed support. Not ‘cool’
for mother always to be present.’
(primary school level; cochlear implant)

Independence: summary comment

Taking all of this into account it seems that a substantial proportion of deaf children in this secondary school age sub-sample were, to varying degrees, experiencing restrictions to the development of self-reliance outside of school for deafness-related reasons. While those with greater levels of hearing loss were most likely to experience limitations, sizeable minorities of those with lesser levels were also limited in the kinds of independence activities normally associated with their age groups. As with other areas of data from the survey, without more information (such as greater depth of detail, and perspectives of the young people themselves), it is not possible to link this directly to likely outcomes – in particular to mental health issues. However, it does seem that the evidence confirms that some deaf children and young people were likely to experience a restrictive impact on the development of their social and emotional independence.

General summary comment

While almost half of the sub-group reported deafness-related difficulties, in relation to independence indicators, this meant that just over half did not. Within the other areas considered in this chapter, larger proportions of respondents indicated apparent lack of barriers to their deaf children's peer relationships and participation in activities. This is heartening, but the fact remains that, in addition to restrictions to the independence-related restrictions just discussed, sizeable minorities seemed to be having what could be described as 'visitorship-type' experiences when participating in mainstream 'hearing' networks outside of school and attending cultural events and activities. A few were also having such marginalising experiences when introduced to networks of deaf peers, either informally or through organised activities.

In the following chapter, key details of these findings, and those from the previous chapter, will be explored through the lens of symbolic capital.

Chapter Six: Discussion

Throughout the preceding chapters, it has frequently been stressed that there are limitations to the data, which restrict the generalisability of findings. Consequently, I will begin this chapter by summarising these restrictions, as being the context in which all analysis should be viewed. The second section of the chapter explores the main findings through the lens of symbolic capital.

Limitations to data and data analysis

Questionnaire design issues

The fact that there are disadvantages as well as advantages in distributing a postal survey as a research instrument was discussed in the methodology chapter. Concerns listed as potential drawbacks were largely borne out, to varying degrees. In particular, the lack of control over respondents' interpretation of the content of questions was noted on a number of occasions as problematic, despite the amount of effort which had been expended in trying to ensure that questions were clear and unambiguous. For example, the meanings of: 'quality of communication'; 'difficulties relating to deafness', and 'strong' versus 'limited' friendships, appeared to have been interpreted in different ways by respondents – thus weakening the potential strength of findings crucial to the research questions. The numerical ordering of the scale used for eliciting opinion in the Quality of Communication Question was shown to have been counterintuitive for some parents, causing extra work in perusing all responses and impacting on robustness of findings. Further piloting may have helped to tighten up the language and, had resources permitted, structured interviews would have undoubtedly provided much greater levels of consistency and accuracy.

Another major criticism of postal questionnaires raised by research methods literature, was the relatively high risk of non-completion, due to the lack of motivating personal contact. Despite the benefits of the volunteer network, the use

of third parties to distribute survey packs meant that it was not possible to either be sure of the final response rate or to make direct chase-up contact with all potential respondents, as recommended by Cohen et al. (2000). The possible impact on motivation may well have been a major factor in the relatively low response rate (bearing in mind that a proxy rate was eventually used, which may well be an underestimate).

Without detailed follow-up, it is not possible to be certain about the reasons why a large number of potential respondents did not complete and return the forms – and many factors may have contributed. However, it is probable that literacy issues may have also discouraged some people, in spite of all attempts to make the content accessible. The fact that there was a slight skew of respondent households towards the highest Standard Occupational Classification level may be an indicator of such discouragement.

The impact of the compromises and ‘trade-offs’ involved in the design process were also explicated in the methodology chapter. Some related to the limitations inherent in paper-based questionnaires. For example, limitations to the richness of data resulting from compromises between the need to include sufficiently nuanced detail and the need for a suitably brief instrument were highlighted, as well as the risk of ambiguity where data is inductively gleaned from open comments. In the latter case this was exemplified by the fact that lack of confidence was raised as something which prevented participation in activities, but that it was not possible to tell whether this was a cause or effect of communication barriers.

Other trade-offs resulted from the involvement of parents as research co-designers, rather than as members of a reference group. Trying to ensure that views were given equal weight led to compromises, such as those highlighted in relation to the inclusion of questions relating to socio-economic status and cultural activities (while it was also admitted that the balance of power tended to lie with the research team). It could also be argued that, whilst the ethical and epistemological advantages of this effort to balance power between academic and experiential standpoints are

sound, the consequent ‘horse-trading’ politics involved in the decision-making process carries inherent risks, such as the potential for missing key elements and themes, or for giving too narrow a range of closed options for questions, such as that which elicited information about types of out-of-school activities attended (ie only organised clubs were included).

The omission of clearly-defined options on cultural activities specific to Deaf groups was potentially problematic, as will be described later in this chapter.

Comparator populations

While it is argued that there is heuristic value in considering data from this population of deaf children and their parents in a ‘standalone’ sense, it is recognised that comparison of situations with those in the general population, whenever feasible, would have added weight to findings. For example, it would have been valuable to have been able to compare parents’ views about quality of communication between their deaf child and individual family members with data about communication between hearing children and family members. It did not prove possible to locate comparator data for this and other similar areas within the study, after the question had already been devised. However, it is feasible that more rigorous literature search during the design phase of the study may have enabled questions devised by the collaborative group to be more geared towards such comparative analysis.

In terms of comparison between the respondent population of parents and that of all parents in Scotland, the Scottish Household Survey team had indicated willingness to provide tailored statistics which would have enabled direct comparison of indicators of parental socio-economic status. However, this did not prove possible. As indicated elsewhere, the fact that the nearest comparator population comprised parents of 15/16 year-olds was potentially problematic, as it was likely to be skewed towards an older age group. However, efforts were made to counter this effect when comparing parent employment patterns, by using data relating only to secondary-age pupils.

Impact of low response rate

For reasons as described, the survey was targeted at a whole population, rather than at a specific sample. However, given the fact that it is not possible to be sure of what information non-respondents would have contributed, perhaps a targeted sample would have provided a higher level of rigour in reporting findings. As it transpired, this was counterbalanced, to some degree, by the fact that the Group 1 sub-sample was shown to be reasonably representative of main comparator populations, with the exception of a highly significant skew towards mothers doing unpaid work at home (SSLS comparator), which was a finding in itself, and lesser-level skews towards:

- pre-school age children (ADPS comparator);
- severely deaf and cochlear implanted pupils (ADPS comparator);
- mainstream school placements among pupils (ADPS comparator);
- families using BSL as a main language at home (ADPS comparator);
- fathers not working full time (SSLS comparator); and
- higher household Standard Occupational Category (SSLS comparator).

Construction of the 'learning disability' variable

A case was made that particular care is needed whenever information about medical conditions, syndromes and other specific physical or learning disabilities is included as an indication of intrinsic barriers to learning – and that current comparator populations are imperfect in this respect. The coding system used within this study was an attempt to increase the likelihood of establishing the impact on learning of any single or multiple combinations of specific disabilities and difficulties.

While it was argued that the resulting construct was the best route available for the meaningful identification of likely impact on learning, it was acknowledged that it was not, in itself, a fully robust measure: it was not possible to arrange rigorous checks by relevant professionals, other than for data relating to eye conditions.

Therefore it was suggested that caution is needed in drawing conclusions based on this data, both in terms of an apparent indication that children with ‘learning-related difficulties’ were under-represented, and in relation to all findings where those with ‘learning-related difficulties’ have been excluded.

Single perspective/single method

A final limitation emanates from the fact that the survey only gives one perspective: that of parents, the vast majority of whom were mothers; and gives that perspective by the use of only one method: a postal survey. The lack of perspective of young deaf people themselves has been raised on a number of occasions, particularly in the context of evidence that the parent/deaf child perspectives can differ (for example, in relation to definition of ‘friendships’ and to opinion on quality of communication with family members).

Also, whilst the use of a mix of both closed and open questions was aimed at producing optimal breadth and depth of data within the funding available, additional stages, involving more in-depth, qualitative study would have considerably boosted the extent to which the resulting data could have reflected real-life complexities in the most meaningful way. For example, the apparent contradiction between the high levels of quality communication between cochlear implanted children and their parents and the high levels of difficulties reported in key discursive interactions within the same dyads could have been illuminated by supplementary in-depth interviews with both parents and children/young people, and/or by observations.

Most of the above limitations related to pragmatic trade-offs of various kinds: need for detail vs need for brevity; potential for whole population coverage vs loss of control of distribution; need for methodological triangulation vs restricted funding, and the need for genuine collaboration with stakeholders vs time and funding restraints.

Quantitative treatment of qualitative data

As discussed in chapter 2, while I have argued that the qualitative data gained from comments to open questions have value in themselves, this is in the context of the fact that the quantitative treatment of the coded data could be viewed as lacking validity, particularly as fewer than one third of respondents ever provided such comments in relation to any one question.

Despite all of the limitations set out here - and the fact that loss of ADPS funding severely restricted the potential to explore the links between family factors and achievement – it is posited that the findings from the data are still valuable in terms of pinpointing areas for future, more in-depth study. Furthermore, as described in chapter 2, the collaborative process was arguably a valuable experience, in itself, for all those involved.

I now return to the research questions, exploring findings through the lens of symbolic capital before, in the final chapter, considering the implications for future research and for policy and professional practice within specialist education services.

As the size and nature of sub-populations varied, depending on the specific data being explored, the following list is a reminder of the composition of the various sub-samples concerned.

| Survey question | Composition of sub-sample (deaf children of respondents) |
|-----------------------------------|--|
| Quality of Communication Question | Group 1; no 'learning-related difficulties*'; aged over 2 years (n=263) |
| Discussion Question | Group 1; no 'learning-related difficulties*'; school age only (n=233) |
| Hearing Friendships Question | Group 1; no 'learning-related difficulties*'; aged over 2 years (n=263) |
| Deaf Friendships Question | Group 1; no 'learning-related difficulties*'; aged over 2 years (n=263) |
| Activities Question | Group 1; no 'learning-related difficulties*'; school-age only (n=233) |
| Cultural Activities Question | Group 1; no 'learning-related difficulties*'; school-age only (n=233) |
| Independence Question | Group 1; no 'learning-related difficulties*'; secondary school age (n=103) |

*as defined in chart 4.4

Symbolic capital and quality of communication between deaf children and family members.

Accepting Bourdieu's notion of linguistic capital as the 'appropriating capacity' within a child's 'habitus' (Bourdieu, 1986), and Coleman's argument that the quality of communication within the parent-child dyad has particular significance to a child's social and cognitive development (Coleman, 1994), the fact that most respondents reported good or very good communication between their deaf child and themselves is heartening.

However, the more nuanced data relating to key discursive situations demonstrated higher levels of difficulties in hearing parent/deaf child communication than those suggested by the data on quality of communication – particularly in relation to language and conceptual problems, and particularly where the children and young people concerned had greater levels of hearing loss (see separate section, below, on children with cochlear implants). Bearing in mind that none of this group were reported as having learning difficulties, this may imply some level of under-development of linguistic potential, and its appropriating capacity, among some children of hearing parents, as has been found in other research. It also suggests the existence of particular challenges for these parents in their 'primary pedagogical work' (Bourdieu & Passeron, 1977) with their deaf child, and in the development of bonding capital, essential to their child's emotionally secure place within the family unit. Particular concerns have been raised about the early years stage, where the language acquisitional capacity of the habitus is at a high point, and where there was a lower proportion of parents reporting high quality communication compared to other educational stages.

Relationships between all family members can be seen as being locations of the 'information channel' form of social capital (Coleman, 1988). In addition, the bonding capital inherent in relationships with both siblings and grandparents has been shown to be potentially of special significance. However, in households where parents were hearing, evidence shows a pattern of concentric family communication

circles, with mother/child dyad at the centre; this is in the context of an employment activity profile showing that mothers were highly likely to spend more time at home than mothers generally. Some evidence has been presented here which may also indicate a possibility of a slightly increased tendency for fathers to move towards a more central role (bearing in mind the skew towards higher social class within the sample). The family communication pattern also shows a likelihood of communication quality decreasing outwards to grandparents and other extended family on the outer ring. Whilst profiles were again diverse, this indicated, for some children, a restriction in the potential for accumulating the benefits of both forms of social capital in their relationships with hearing grandparents and, to a lesser extent, with hearing siblings – with potential educational and psycho-social implications.

The low numbers of children where minority languages were spoken at home means that little can be drawn from the evidence other than the complexity of individual situations, and the need to explore implications of the possibility that it is more likely than previously for parents to be encouraged by professionals to use their native language with the deaf child at home.

The fact that all of the all-deaf-parent households reported both high quality communication and problem-free discussion with their deaf children fulfils expectation raised by other research, suggesting that having deaf parents provides greater potential for relatively trouble-free accumulation of linguistic and bonding capital in the ‘primordial domain’.

However, it was also stressed that just over half of the hearing respondents reported similar levels of quality - and a similar absence of difficulties in discursive interactions. Bearing in mind the possibility that parents interpreted the response scale differently, both groups of children with hearing parents – those with and those without reported difficulties - were shown to be diverse in terms of a range of factors, including permutations of languages and language modes – again a feature of other cited studies.

Coleman illustrates his concept of 'intergenerational closure' by reference to the degree to which children and their parents have respective bonding networks which are close enough to give rise to supportive and shared 'effective norms' for each generational network – norms which organically develop guidelines for productive behaviour (Coleman, 1988). It could be posited that both hearing and deaf networks of parents (and their deaf children) are likely to have some degree of intergenerational closure, but that there may be a gap between the two networks - and therefore of norm-building bridging capital - despite the fact that the parents all share the situation of bringing up deaf children and may have distinctive 'effective norms' to exchange (eg factors facilitating fluent linguistic experiences within deaf families). As described in the methodology chapter, one of the most powerful aspects of the survey pilot day was the reaction of hearing parents to meeting deaf parents for the first time. Also, the children involved have shared experience of deafness, and, possibly, a shared 'different centre' of identity (Padden & Humphries, 1988), whether or not this would be in addition to other identity 'centres'. In short, there seems to be potential for more productive bridging between the two networks.

As with data about deaf parents, the situation of communication with deaf siblings was markedly more positive than that with hearing siblings, although there was less qualitative information to provide more depth. It may be that, seen in conjunction with the parental data, above, a deeper level of shared identity with deaf family members is implied, along the lines of the 'different centre' suggested by Padden and Humphries, but the data do not enable such a level of exploration.

Symbolic capital and social life: friendships

Strong peer friendships have been assumed to be powerful sites of social capital, being functional in terms of informal learning and in terms of the formation of networks which may provide economic as well as social benefit in the future.

Data on friendship patterns were seated within the context of the ‘inclusion agenda’, which has dictated an increased likelihood that deaf children will be placed in mainstream schools near their homes, rather than in special schools often at a distance away – thus increasing the chance that their peer group will be mostly hearing rather than deaf, both inside and outside of school. A key assumption here is that the opportunities for increased social and cultural capital within dominant, hearing, networks (including institutional forms of capital, such as educational qualifications), will have a direct impact on the building of economic capital in adulthood. Only eleven of the sub-group attended specialist schools for deaf children. Hence it is no surprise that all but two children were reported to have friendships of some kind with hearing children and, again, it is encouraging that two thirds of sub-group respondents reported strong friendships and no deafness-related difficulties in these relationships.

However, for the remaining third, common reports of communication barriers suggested a similar pattern to that reported in other studies: where the deaf child could find full access to peer group communication was restricted, and could experience marginalisation by peers. It therefore seems that, for some children, inclusive education was proving to be, to some extent, an excluding experience, in terms of the strength of bonding with their hearing peer group – suggesting levels of ‘visitorship’ rather than ‘membership’, as described by Antia et al. (2002).

The greater the hearing loss level, and the more intensive the specialist nature of the school placement, the greater the likelihood of reportedly weak (or in two cases, non-existent) bonds with hearing friends. Nevertheless, there was a level of diversity among those with, and those without, reported difficulties: almost a third of parents of moderately deaf children in mainstream indicated deafness-related barriers. Meanwhile, just over half of the sub-sample had friendships with other deaf children. In this case, the greater the levels of hearing loss, and of usage of sign language, and the more intensive the support level of the school placement, the greater the likelihood of reportedly strong bonds with deaf friends.

There was not enough depth of data to be able to draw firm conclusions about the extent to which the concepts of an alternative cultural group or ‘different centre’ may apply here, but there was certainly evidence of special significance being accorded to strong deaf/deaf friendships – and not always in relation to the numbers of deaf children likely to be in contact at school. The notion of an alternative bonding network was borne out to this extent, but reports of difficulties in accessing this network were common, usually in terms of lack of deaf peers in the home locality – exacerbated by the relatively sparse spread of population throughout much of Scotland. The picture emerges of trade-offs between the benefits of having previously been able to maintain and develop this shared identity network among a critical mass of deaf peers in boarding schools for deaf children, in pre-inclusion days, versus the benefits predicted by inclusion-driven opportunities for maintaining and developing networks within the dominant hearing society, at home and in mainstream school placements (in addition to expected advantages in educational resources).

To a limited extent, specially resourced units within mainstream schools may have taken the place of separate schools, for some deaf children, in terms of being a focus of deaf friendships - often a distance away from home, but always as day, rather than a boarding, situations: a more limited trade-off was identified within the data – between these specialised placements and more local mainstream settings where a child or young person might be the only deaf pupil (and least likely to have deaf friends). The proportion of deaf pupils in unit-related placements with a strong deaf/weak hearing friendship pattern seems to bear out the capacity of units to facilitate strong deaf network bonding. Thus, while the opportunities for developing stronger bonds with hearing families and friends at home are greater than were provided by boarding placements at specialist schools in the past, it appears that it does not immediately follow that strong bonding with both deaf and hearing networks will easily and automatically be facilitated, merely by providing access to both networks in this way.

Having said this, it does seem that unit-related placements can indeed provide a location for the building of 'bridging capital' between hearing and deaf bonding networks: around a third of the pupils in these situations were reported as having a strong hearing/strong deaf friendship pattern. Other common characteristics of those with this pattern were cochlear implantation and sign bilingual communication – suggesting that both of these factors may also facilitate bridging.

Parents also had a role in enabling bridging capital to take place between the two networks, as have been reported in other studies, by providing transport and general encouragement. This will be further explored later, in relation to activities.

As might have been predicted, nearly all of the small number of children and young people with deaf parents were reported as having strong deaf friendships – the only exception was because the deaf parent felt that a unit placement did not provide a large enough deaf peer group, compared to that which would have been provided by a school for deaf children. Perhaps surprisingly, the presence of one deaf and one hearing parent did not seem, in itself, to necessarily provide the environment for bridging between deaf and hearing networks.

It has been argued that the existence of strong, linguistic and cultural bonding networks among deaf people, and the experience of a 'different centre', can have profound implications for a deaf child's habitus. The literature has shown that a normative assumption that hearing networks are superior, and concerns that accumulation of social, cultural and economic capital in these networks could be jeopardized by strong membership of a BSL-using Deaf community, can lead to an 'either/or' perspective and, in symbolic capital terms, underpin identity tensions at the heart of the habitus of the deaf child. The complexity which can characterise such tensions was exemplified by one deaf respondent mother, whose husband/partner was hearing. In the following quote she poignantly indicates her own sense of deafness as inferiority – something which seems to underpin her account of lack of confidence, despite having a family network of deaf members through past generations:

‘Generally we have tried to get by on our own with support for and from one another. We have hearing problems throughout the whole family, from generation to generation and it has become accepted that this is how we are and we just have to accept and get on with it. Some of the family accept any offers of help, others try to be normal not letting deafness get in the way of anything. This is the case for my child but as a parent I lack the confidence both to go it alone or to back down and seek help.’
(mother of moderately deaf, secondary age pupil)

In the context of identity tensions, particular concerns were raised about those children who appeared to be isolated from both deaf and hearing networks. The likelihood of ‘falling between two worlds’ appeared to rise with hearing loss level, and most had English as first language. No children of deaf parents were in this group. Instances were highlighted of a few children whose bonding capital among hearing networks appeared to be particularly restricted, but who had little or no inroad into relationships with deaf peers. Further challenges posed by individual multi-lingual and multi-cultural family situations were also raised – with some individual children’s situations being noted as particularly problematic, both within and outwith the family circle.

Although some children without sign skills were reported as being marginalised within deaf groups where BSL was used, for a few others, a combination of agency and circumstance (which arguably could be described as ‘resilience’, as will be discussed later) seemed to enable some ‘oral’ children to transcend this ‘visitorship’-type experience, at least to the extent that parents reported their enjoyment of the social events concerned.

Once again, the complexity of inter-relations between a deaf child’s linguistic aptitudes, hearing loss level, capacities, dispositions, and external influences and opportunities is evident. Therefore, rather than proposing a normative prescription of an ideal balance of full ‘membership’ of both deaf and hearing networks, the challenge in responding to this diversity seems to be: to ensure that deaf networks are accorded appropriately high status; to enrich opportunities for bonding in both

networks, and to facilitate bridging between them. It would seem that participation in structured activities is a potentially fertile means of providing such opportunities.

Symbolic capital and social life: structured activities

Structured activities can be viewed as being locations for the accumulation of cultural capital, in that the learning of knowledge and skills is often a clear aim. The balance between this goal and a more social aim - of providing an environment to foster peer bonding, and therefore social capital - varies between types of activity; from highly institutionalised uniformed groups, through specific skills-based clubs to informal youth groups.

As with data on friendships, around two thirds of respondents reported no deafness-related problems in their deaf children's full participation in activities outside of school. The vast majority of the third who reported problems in accessing mainstream activities described linguistic access barriers of some kind, with the highest proportion relating to missing or misunderstanding information from both hearing leaders and hearing peers. This, coupled with reported psycho-social problems of isolation, lack of confidence and anxiety, again paints a picture, for some children, of a 'visitorship' level of participation rather than 'membership' – impacting negatively on accumulation of both cultural and bonding capitals.

Although there was some correlation between level of hearing loss and likelihood of problems, the presence of barriers across all hearing loss levels, from moderate upwards, was striking. In fact missing information from instructors was more often reported as problematic in relation to moderately/severely deaf children than to those who were profoundly deaf or cochlear-implanted. What were, arguably, more significant than hearing loss levels, per se, were the types of strategies used by the deaf child for accessing information and for contributing to group discussion (for example: audition, lipreading, speech and BSL interpretation) – which do not fit neatly into hearing loss categorisation.

For example, issues relating to acoustically hostile environments, such as outdoor playing fields, gyms and swimming pools, and to difficulties relating to speech amplification, were relevant to those children who accessed information through audition, enhanced by hearing aids or cochlear implants. As profoundly deaf pupils were least likely to use audition for accessing information, it was not surprising that only one of them was reported as experiencing audition-related barriers - but there was still one. The strong correlation between hearing loss levels and use of sign language means that those with more significant hearing losses were more likely to use BSL, but not all those with profound losses did so – even though the Group 1 sample was shown to have a slight bias towards BSL users.

Strategies used by deaf children are likely to be the same as those used within school – mostly supported by assessment and interventions from specialist professional staff. Each strategy, or combination of strategies, used by a child for receiving information, and contributing to discussion, in any given mainstream situation, is a manifestation of the synthesis between: the child's chosen language (signed or spoken), the range of strategies at the child's disposal (for example: types of amplification; lip-reading; speech; some form of manually coded English or BSL interpretation); the capacity of the child to choose between, and to maximise, the use of strategies; and the quality of conditions needed for successful implementation.

Returning to the notion of language as an 'appropriating capacity' within the habitus, one would hope that the strategies used by each 'little linguist' – each 'social actor' – would always emanate from the optimal development of innate linguistic aptitudes and abilities. However, concerns have already been raised that the choice of linguistic strategies is likely to have been restricted to some extent (particularly with regard to assessment and quality resources in sign language, but also in relation to the use of lip-reading), and may be more to do with geographical variation of educational service language approaches than the result of well-resourced, holistic, 'no exclusion' assessment and intervention (Grimes, 2008).

Whether or not individual strategies always develop out of individual linguistic potential, successful implementation also depends on the conditions within which the strategy is being used, as noted above. It is clear that the potential level of success was sometimes being compromised by specific environments (for example: acoustically hostile situations; quick-fire group discussions); by excluding attitudes and behaviour of some leaders and peers, and by lack of BSL resources. Examples ranged from staff behaviour which was clearly discriminatory to some examples of good 'deaf awareness' practice which were noted as making a positive difference to full participation of the children concerned.

The difficulties reported regarding participation in sporting activities have particular significance, in terms of the enhancement of bonding and cultural capital, and of resultant self esteem, which can be gained from the accumulation of physical capital alongside hearing peers. In some cases it appears that relatively small adaptations by leaders and organisers would have made a difference to participation (for example, creating more ideal conditions for lip-reading); whereas other barriers appear more challenging to overcome (for example the quick-fire characteristic of large group discussions).

As with data relating to friendships, the levels of lack of confidence and isolation reported by respondents was again of concern, this time particularly among profoundly deaf children and young people, and especially in view of the fact that there may have been some under-reporting of such psycho-social issues.

Other children, however, of varying hearing loss levels, were reported as developing their own ways around linguistic barriers and gaining confidence through the experience. The concept of resilience seems to be relevant here, in terms of 'the successful navigation of being deaf in a world...which may commonly deny, disable or exclude [deaf children and young people].' (Young et al., 2008:52). Young et al.'s plea for exploration of resilience capacity to include a structural, societal level, in addition to individual and family levels, could be seen to fit with the all-encompassing nature of habitus and symbolic capital – assuming a synthesis of: the

infinite range of permutations of: individual linguistic aptitudes, abilities and dispositions; the extent to which the child's 'appropriating capacity' of language is unlocked through family relationships and professional intervention; and the accessibility of different communicative environments.

As expected from the literature, a few parents provided opportunities for the development of 'bridging capital' – this time between their deaf child and hearing networks, in order to facilitate their child's understanding of instructions from leaders and his or her bonding with hearing participants. This was largely done by taking on the role of assistant instructor or interpreter.

No deaf parents were in this 'bridging capital' group and, in fact, having been seen to have an advantage in terms of quality of communication with their deaf children, a different picture emerged for deaf parents, in relation to their children's participation in mainstream activities. There was only a small number of deaf parents but, bearing in mind some confounding influences, it was still interesting that twice as many deaf parents as hearing parents reported that their children had linguistic access and psycho-social barriers to participation.

Perhaps surprisingly, none of the children of deaf families were said to attend specialist after-school and youth groups for deaf children and young people. It may well be that the children concerned had opportunities to further develop bonds with deaf networks in more informal social activities, which parents did not record in the survey form. However it is not possible to know this from survey data.

Both these type of specialist deaf groups, and occasional events run by the National Deaf Children's Society, generally seemed to fulfil the role which might be expected: that of a strong shared-identity deaf environment. The NDCS events have already been particularly highlighted as providing significant bonding opportunities. However, some reports of difficulties in participation were telling, in terms of the identity-related complexity of deaf and hearing networks. The linguistic exclusion 'visitorship' experiences of some children in the all-deaf activity deaf groups seemed

parallel to those being experienced by other deaf children within the hearing networks of mainstream activities. However, in their case, their ‘otherness’ was reported as being due to lack of sign language skills in signing environments. Again there is a sense that there are two bonding networks available, but that some children are unable to develop strong capital in either – being ‘between two worlds’.

Having already noted evidence of hearing parents providing the opportunity for building bridging capital in relation to mainstream groups attended by their deaf children, here hearing parents could be seen to facilitate the accumulation of bridging capital in relation to their children’s access to deaf bonding networks (as in the general friendships section, above). While no conclusive relationship was demonstrated between this situation and socio-economic status, there may still be some link with economic capital, as there are financial implications involved in supporting events at a distance from home (bearing in mind that the Group 1 sample is slightly skewed towards high level of household occupational status). Thus, whilst application of the proxy socio-economic measure revealed, if anything, a greater likelihood of higher class families reporting that their deaf children were experiencing barriers to inclusion in activities, comments from two respondents signified the potential link between economic capital and opportunities for participation – both pointing out that relatively high financial resources enabled more opportunity for facilitating their child’s access to both hearing and deaf networks.

Symbolic capital and social life: cultural activities

Although a case was made at the start of this thesis for not generally exploring or challenging the arbitrariness of dominant cultural values when using the lens of symbolic capital, there were particular concerns about the data relating to attendance at events and activities that fell within the specific definition of ‘culture’. As described in the methodology chapter, there was an acknowledged risk that asking for details of attendance at events which could be described as cultural was normatively charged - implying a valorisation of such ‘cultural arbitraries’. The

degree of success at neutralising the normative implications within the Cultural Activities Question by providing a broad choice of categories, and by careful consideration of wording, is debatable. There was some evidence of a socio-economic effect in response, with a slight skew towards highest household occupational class among those who reported attendance in all categories of activities other than watching sport.

Bearing this in mind, again it is positive that the majority of respondents (this time almost three quarters) did not report that their child had any difficulties in attending or participating in cultural events and activities. As with social activities, there was an unsurprising correlation between reports of difficulties among the other 27% and the level of hearing loss/whether BSL was a first language - and the same concerns apply in relation to whether the available range and quality of linguistic access strategies used by the children and young people were optimising their individual linguistic potential.

Attendance at cultural activities implies a more socially passive experience than participation in the kind of social activities discussed in the previous section. Here, cultural and social capital is acquired more through being informed or being entertained than through sharing activities and discussion with peers. Thus, specific linguistic strategies cited by parents as being compromised were those related to receiving information. In particular: where audition was used, problems related to the availability and quality of amplification equipment, such as loop systems; where BSL was used, the lack of BSL resources was the issue, and in cases where reading written English was the preferred strategy, concerns pertained to lack of availability of subtitles. The latter case referred to accessing films at the cinema, which was by far the most popular type of activity. Here the access strategy concerned – reading subtitles - transcended the effect of hearing loss level, in so far as the strategy was reported as being used across all hearing loss levels.

In cases where respondents made general comments about their child not being able to follow what was going on, it is not possible to be sure of which

strategies were proving to be inadequate or were being restricted. However, in most cases of difficulty there was an indication of restriction to participation – of a sense of ‘visitorship’. The parental time and effort devoted to 1:1 interpretation and explanation could be construed as providing the means for accumulation of bridging capital, in order to counter such marginalisation, and again resonates with literature referred to in chapter 1, which indicated that hearing parents often take on a more didactic role than average with their deaf children.

None of the small number of all-deaf-parent-household respondents reported that they took on this role but, as with access to mainstream social activities, a higher proportion than hearing parents stated that their deaf children were experiencing difficulties. Thus, although all deaf children of deaf parents were reported as having high levels of linguistic and bonding capital at home, some were still experiencing ‘visitorship’-type restrictions to the accumulation of cultural and hearing-network bonding capital possible within mainstream out-of-school social and cultural activities.

The fact that Deaf networks have strength, history and distinguishable characteristics is well documented (Padden & Humphries, 1988). As mentioned earlier, there is ongoing debate about whether this can legitimately be described as a separate culture (Turner, 1994). However, returning to the issue of cultural arbitrariness, the lack of a specific category relating to Deaf events and performances in the Cultural Activities Question could be construed, with hindsight, as a further act of ‘symbolic violence’, in Bourdieu’s terms. Although it could be argued that the options provided were broad enough to include, for example, Deaf theatre, Deaf comedy, Deaf arts etc, the lack of a separate category is problematic. For one thing, the omission could have been viewed by respondents as an indication of rejection or belittling of the concept by the research team. Secondly, inclusion of a separate option would have valorised the distinctive cultural nature of Deaf performance (as distinct from interpreted hearing productions). Finally, as there were no mentions of Deaf cultural events within the generic categorisation, it may have provided useful data on deaf children’s experiences in accessing events, which could be seen to

provide potential access to alternative cultural capital as well as to the social capital inherent in all-deaf social activities. However, unintentionally, the opportunity was lost for this.

The deaf child's own agency has been referred to in relation to all stages of child development, from infancy onwards, in the context of the way that child's linguistic aptitudes and their abilities and dispositions synthesise with other influences within the developing habitus. The next section will focus on the concrete manifestations of agency at home, in the transition to self-reliance from adolescence onwards.

Symbolic capital and independence

It was demonstrated, in chapter 1, that parents can find it particularly difficult to take risks involved in encouraging their deaf children to be self-reliant. In social capital terms, it was suggested that Catts' (2008) notion of a continuum within bonding capital could be applied: at one end a parental 'safe and secure platform' from which the child can develop their own bridging capital; and, at the other, the parent as gatekeeper of a locked 'fenced paddock'.

Findings confirmed that over half of the parents in the sub-group were experiencing particular difficulties in taking the risks involved in the transition from the gatekeeper to platform positions, as their children matured through adolescence into adulthood. For some parents, perceiving their child as more vulnerable to danger, and predicting communication barriers with hearing strangers encountered in the course of independent activities, meant that they prevented or restricted the independence of their deaf child to a greater extent than would have been the case with hearing offspring. This particularly applied to travelling on public transport alone and to earning money.

In some cases the impact seemed to be more a case of the parent suffering increased stress, while the young person was acting independently, rather than the parent actually preventing or restricting independent behaviour. Bearing in mind that there may have some level of variation among interpretations of the survey question, the diversity in reports points to the complexity of the interactions between all the potential factors involved – at individual, family and situational levels (including the impact of the child’s own agency) - and often indicates the level of struggle experienced by parents in opening the metaphorical paddock gate. This even applies to the one family of deaf parents in the sub-sample, which appeared to fall into the fenced-paddock category, against expectation.

Although there was a correlation between the child’s level of deafness and the likelihood of parental gate-keeping (see next sub-section regarding young people with cochlear implants), a sizeable minority of young people with lesser degrees of hearing loss were also reported as experiencing greater restrictions than would be the case for hearing peers.

The restrictions experienced could be seen as impacting on the young deaf person’s accumulation of bridging capital, both in terms of their links into adulthood, and their links into hearing society. There is also a high chance of impact on bridging capital in relation to deaf networks, in terms of limitations imposed on visiting deaf friends independently – particularly in the light of evidence that deaf friends tend to live a distance away from each other.

The distinctness of cochlear implanted children’s situation was first raised in the literature review chapter, in the context of concerns that expectations about spoken language outcomes of implantation may impact on the extent to which sign language is part of the spectrum of linguistic choices available to families. It was later explained, in chapter 3, why the ADPS project decided to categorise implantation as if it were a separate hearing loss category – a classification which was then implemented throughout the analysis of findings.

The final section in this chapter applies the conceptual framework of symbolic capital to findings relating to implanted children and young people in the sub-samples explored.

Children and young people with cochlear implants

Implantation could be seen as increasing the deafest children's chances of accumulating both cultural capital and social capital within the dominant, hearing, social structure, through increased access to its spoken language and culture. Evidence was cited, in chapter 1, of implanted children demonstrating increased speech perception and production – particularly those diagnosed early; other, albeit inconclusive, evidence was also noted which indicated positive impact on the accumulation of institutional cultural capital, in the form of educational achievement outcomes.

Resources did not permit the integration of educational outcomes into the data for this thesis, and the family survey questions relating to communication in the family did not assess the level of spoken language perception and production but, rather, focused on functional language, whether that was BSL, some form of manually coded English or, as with the majority, spoken English. It was noted that the majority of secondary-age sub-population of implanted children and young people were disproportionately clustered in the highest social class. The numbers were too low to apply chi-squared statistical test. However, there was no significant statistical difference found between the social class distribution of the whole Group 1 cochlear implanted sub-group and that of the total Group 1 population.

As previously noted the two aspects of the habitus which seem particularly pertinent to deaf children's situation are language and identity. Many of the implanted children in the sample were reported as having no difficulties in family communication, participation in social and cultural activities, or developing age-appropriate independence skills. For some children, however, it seems that, despite

implantation, the likelihood of accumulating linguistic, cultural and bonding cultural capital from communicative interactions in the family, and from participation in mainstream social and cultural activities, was restricted by barriers to communication. The findings relating to the implanted child/hearing parent dyad conveyed a mixed message about communication quality: a very positive general message about quality of communication, but with two fifths reporting difficulty in key types of discursive interactions - mostly concerning discussions conducted in spoken English.

Implanted children in the sample were at least as likely as the severely deaf group to face the kinds of difficulties which could cause restriction in accumulation of bridging and bonding social capital among hearing networks, in terms of participation in social activities and friendships with hearing peers. However, there was also evidence of relatively strong bonding with deaf children within this sub-sample. Overall, the picture is one of variation in levels of identification with deaf and hearing networks.

A relatively high proportion of the implanted group in the sample were reported as having BSL as first language, despite this not being the main language of their hearing parents. This, in itself, may suggest a valorisation of the concept of a 'different centre' by some hearing parents; the relatively high likelihood, among those in the implanted group, of having strong friendships with both deaf and hearing children may suggest the potential for having the 'best of both worlds', as suggested by Wald and Knutson's (2000) study, rather than the more concerning opposite situation noted for some implanted children in the sample – of 'falling between two worlds' – a situation conceivably exacerbated by unrealised expectations of implantation. The extent to which hearing parents of implanted children accord status to deaf networks, and to accumulation of social and cultural capital within these networks, would seem to be a crucial factor here.

However, there are indications that pressures on hearing parents to view implantation as a means of 'normalising' their deaf children into 'hearing, speaking

children' are, if anything, increasing, with developments in early diagnosis and early implantation (Grimes, 2008; Young & Tattersall, 2007). If implantation is conceptualised in purely medical terms as a treatment to 'cure' deafness, which may well be encouraged by professionals (Young et al., 2006), this also can imply a devalorisation of deaf networks and of BSL, thus restricting the potential for accumulation of cultural and bonding capital within deaf networks, including the development of a sign language.

As has already been pointed out, the evidence presented here relates to an implanted group that will not have had the full benefits of early diagnosis and early implantation, which are currently available. It was also noted that implant technology has become increasingly sophisticated and thus more recent implantations are likely to be more efficient. It could thus be argued that those findings relating to limited accumulation of linguistic, cultural and social capital may not be relevant to children who have had such advantages. However, as noted earlier, there is evidence that there is diversity among early-diagnosed and implanted children, which tallies with the conceptual individuality of the habitus, as the synthesis between an implanted, deaf "little linguist's" linguistic aptitudes and preferences and other internal and external influences. This suggests the possibility that some of the variation within the sample may transcend age of implantation – and seems to emphasise the need for further exploration of the relevance of 'no exclusion' language policies for implanted children.

In the following, final, chapter, models will be proffered, within which this possibility, and other key points raised in this discussion, can be located. Implications for policy and practice, as well as for future research will conclude the thesis.

Chapter Seven: Conclusion

This final chapter begins by presenting a very brief overview of key findings, before presenting models which provide frameworks within which the findings can be further considered. It concludes with discussions on implications for policy and practice and on implications for future research.

The majority of respondents, in the sub-samples explored for this study, felt that their deaf children's communication with family members was of high quality, and that their participation in social and cultural activities was not disadvantaged by deafness-related factors. The implication is that, in these key scenarios, their deaf children's capacity for accumulating linguistic, social and cultural capital was similar to that of hearing peers.

However, for a sizeable minority (at least a quarter; a third in most cases), the interaction between the children's deafness and other factors seems to have precipitated difficulties which constituted restrictions to the building of these types of symbolic capital. Almost half of the parents of those of secondary age were also struggling, or felt that they were unable, to allow their children the same level of independence which they would have granted to hearing children of a similar age. It is worth re-emphasising that in all situations the data relate to children without specific learning-related difficulties, as defined by the coding system described in chapter 3.

Limitations of this research prohibit the possibility of drawing conclusions which unequivocally identify causal, and generalisable, factors relating to such findings – although much of what was found confirmed findings from the research literature. However, it has been argued that the thesis has epistemological significance within the field of deaf education, in a heuristic sense, by enabling previously unexplored data on family life and out-of school activity, from a reasonably representative sample of a whole country's population of parents of deaf

children, to be viewed through a symbolic capital lens. The models offered in the next section are aimed at focusing this view.

Social and cultural capital: two models

The relationships between linguistic, cultural and social capital, as described earlier in this thesis, are complex and symbiotic. As such, any attempt to condense these relationships into easy-to-read models will inevitably be simplistic. With this proviso, I have constructed two types of model: one which foregrounds findings relating to relationships, and thus social capital; and one which focuses on findings related to the deaf child's development of capacities for making informed linguistic choices, and thus more clearly features linguistic and cultural capital.

The models presuppose that some children's capacities may optimally be developed by the acquisition of a sign language as well as a spoken language, as evidenced by Leigh (2008), whether or not they are diagnosed early and whether or not they have cochlear implants.

Discussion in the previous chapter identified factors which affected the likelihood of difficulties being experienced (for example, level of hearing loss), but also persistently indicated unexplained diversity. The models do not repeat the detail of this, but provide frameworks within which the key findings, and subsequent recommendations for policy, practice and future research, can be viewed.

Model 1(a) and 1(b): Deaf and Hearing Networks

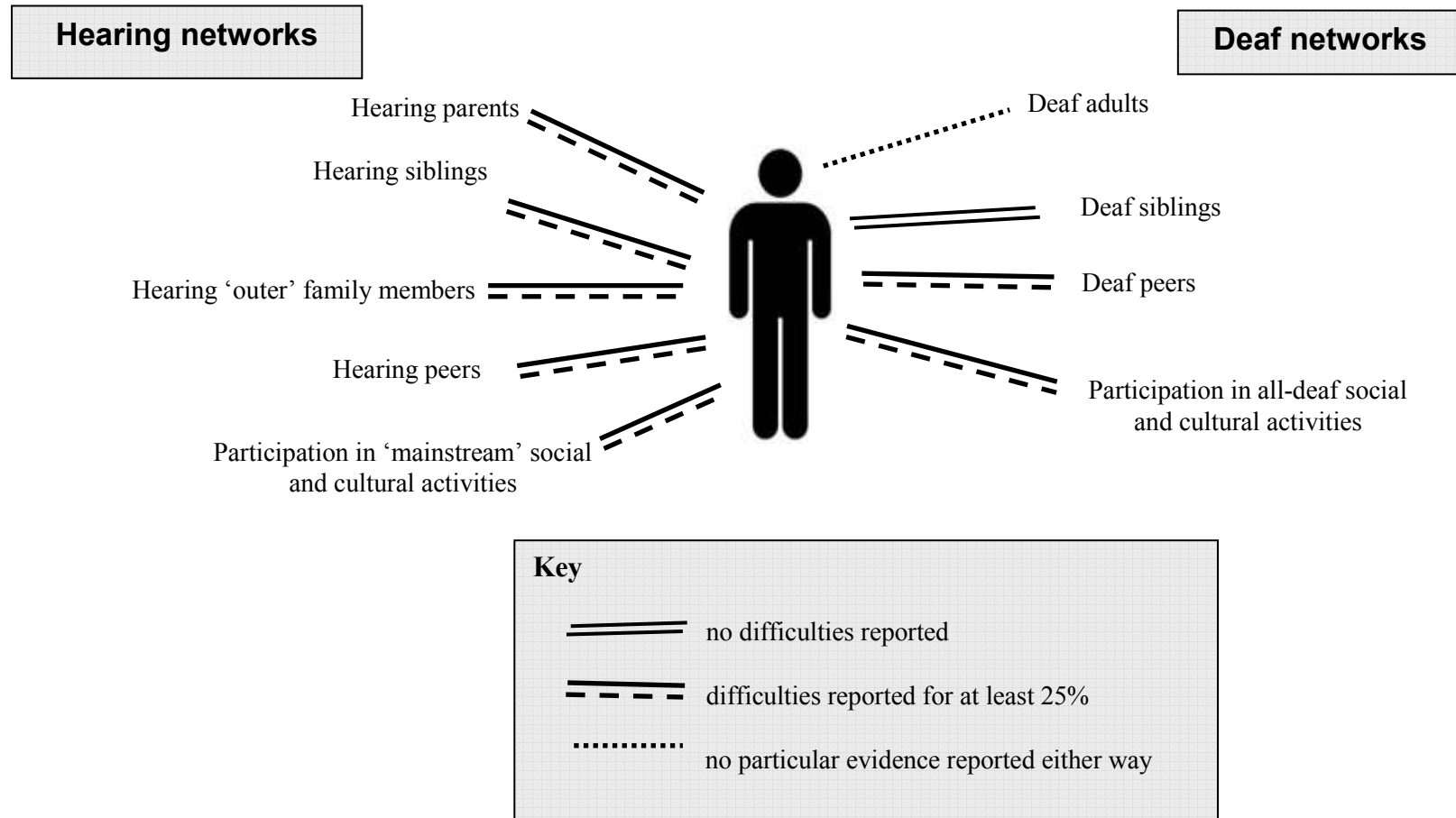
This model depicts the deaf child at the centre of the relationships and situations highlighted in this thesis, within which social capital can be accumulated in both deaf and hearing networks. Connecting channels are circumscribed by either two solid lines or one solid and one broken line. Channels with two solid lines represent relationships where no deafness-related barriers were reported by respondents; where there is one solid and one broken line, this indicates that some

respondents reported barriers and some did not. The solid/broken combination, therefore, indicates that the accumulation of social capital, or of both social and cultural capital, was restricted to some degree in some cases.

Bearing in mind the low numbers involved, the experiences of deaf children of deaf parents was shown to be distinctive, and so the model is split into two diagrams: 1(a), representing deaf children of hearing parents, and 1(b), representing deaf children of all-deaf-parent households.

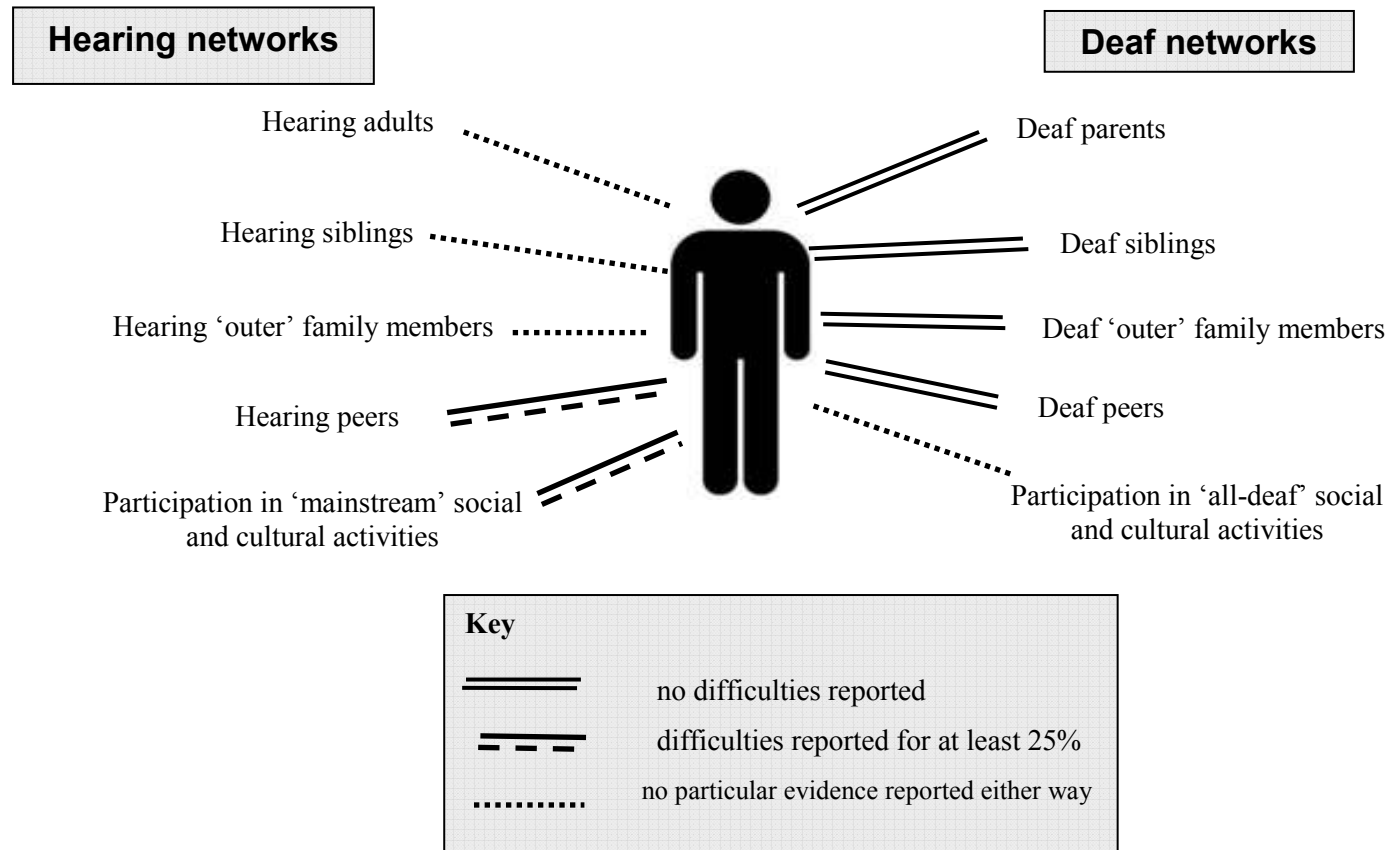
Model 1(a)

Participation in deaf and hearing networks among deaf children of all-hearing parent households
(Group 1; no 'learning-related' difficulties* [n=322])



Model 1(b)

Participation in deaf and hearing networks among deaf children of all-deaf parent households (Group 1; no 'learning-related' difficulties* [n=17])



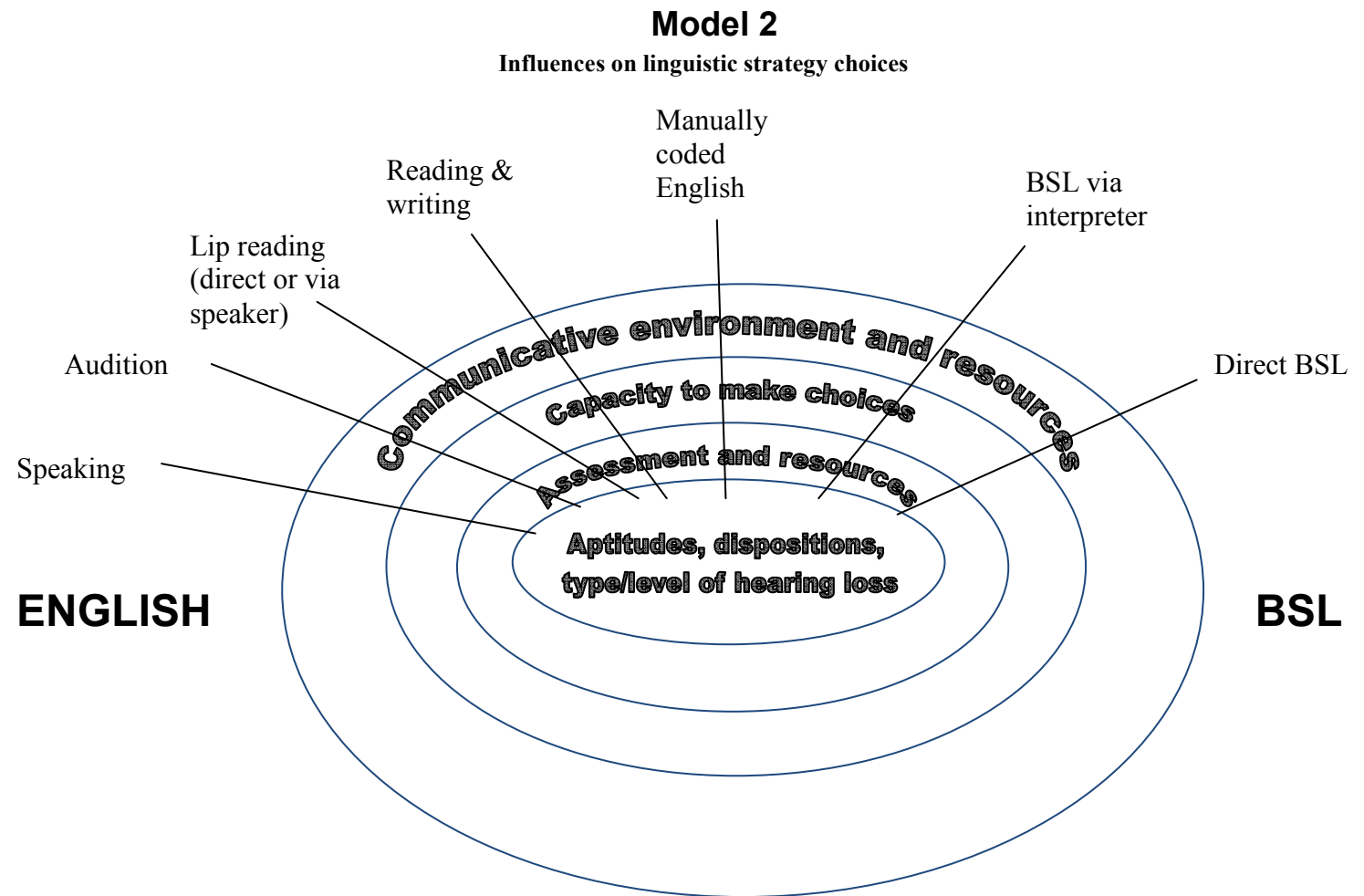
Model 2: Linguistic strategies

Throughout this thesis, deaf children have been portrayed as social actors; beginning life, like their hearing peers, as ‘little linguists’. The notion of habitus has been used to symbolically depict the complex core of each child - the synthesis of their aptitudes, dispositions and other internal, and external, influences. It has been seen as being a particularly significant concept, due to the centrality of the ‘appropriating capacity’ of language – language and communication being central to the distinctiveness of deaf children’s developmental situations – and to the fact that it recognises and embraces the complexities underlying individual diversity.

In the previous chapter, the sections on participation in mainstream social and cultural activities particularly highlighted the types of linguistic strategies used by deaf children – questioning how it can be known that the most appropriate strategies are being employed by deaf children if the range of assessments and options has been restricted, and identifying barriers to their optimal exploitation.

Model 2 views the spectrum of linguistic strategies in the context of the child’s habitus, which is depicted as an inner core of innate aptitudes and dispositions surrounded by key external influences. Hearing loss level is included in the core, but *functional* hearing loss level involves interaction between this and the other factors. The left and right sides of the diagram represent spoken language and BSL, respectively. The synthesis of the interaction between the innate inner core and the outlying factors is portrayed as fundamental to the child’s capacity to optimise linguistic capital and to make informed choices about language and communication.

Bearing these representations in mind, the implications of findings for policy and practice development, as well as for future research, will now be considered.



Implications for policy and for service provision

‘No exclusion’, holistic, assessment and support interventions

Assuming the legitimacy of the concept of habitus, and of the integral constituents and influences depicted in Model 2, then there is logically a need for a comprehensive assessment and support package for deaf children and their families which would optimise both the child’s linguistic capital, with its appropriating capacity, and the accumulation of social and cultural capital inhering in family and peer relationships, as portrayed in Model 1.

It seems, from the perspective of parent respondents, that, within the parameters as defined by this data, whatever individual packages had been provided may have suited the majority of situations – particularly, but not exclusively – where children had lesser levels of hearing loss. However, diversity among the sizeable group who were experiencing barriers to the building of such linguistic, cultural and social capital, coupled with evidence, within the literature, of narrowly-defined assessment and support from services (Grimes, 2008; Rodd & Young, 2009), suggest implications for policy and research at conceptual, strategic and practical levels.

It is not possible to be sure whether a universal ‘no exclusion’, provision of high quality sign-bilingual assessments and services, presented within the context of a positive ‘little linguist’ conceptualisation of deafness, and a holistic inclusion of family and environmental factors, would have meant relatively problem-free family and peer group communication, as well as full participation in activities, for those children and young people reported as experiencing deafness-related difficulties.

However, the known restrictions to the provision of high quality BSL in the linguistic spectrum of assessments and resources are likely to have limited the extent to which any aptitudes, dispositions and situations which may have naturally lent themselves to the development of a sign language could have been exploited. This is not to say that the relatively high level of assessments and resources in spoken language development could not be improved upon – developments in technology, in

particular, are happening at a rapid rate. Rather, it is proposed that, in order to respond to the individuality of deaf children's habits, there is a need to address the imbalance across the linguistic spectrum of assessments and resources, in the context of a holistic intervention approach involving family and environmental factors.

Where a narrow, impairment-focused mindset prevails, as Rodd and Young (2009) found to be the case among services in England, it inevitably perpetuates such an imbalance, and is also likely to preclude, or limit, access to d/Deaf social and cultural networks, alongside access to hearing networks. This is despite evidence, such as that presented here, that they can be important locations of social capital, and that a sizeable group of deaf children are marginalised in hearing networks. Young et al. (2008:44) posit that, where deafness is seen, in Padden's terms, as a culturo-linguistic identity with a 'different centre' rather than simply as an audiological impairment, then:

'the risk associated with it concerns the failure to enable deaf children to have developmental opportunities to realise that identity.'

The challenge for hearing parents should not be underestimated. As noted earlier, many have had no prior experience of deafness, but a 'no exclusion' model implies the possibility that they and their family face the need to: conceptualise and accept that their deaf child may have a natural language and socio-cultural identification which is different to the rest of the family; embrace both the language and the ramifications of their child potentially having two 'centres' of identity; and integrate the language and socio-cultural network into the family's everyday life. The slightly-higher-than-expected proportion of families in the survey population who had BSL as a main language at home, had integrated it into their lives to some extent. However, the paucity of BSL assessments, and of high quality resources within specialist services make it highly unlikely that even these children and their families were being enabled to optimise its use, both in terms of the child's accumulation of linguistic capital and of bridging between hearing family members

and Deaf networks. The number of these parents who bemoaned the lack of easily-accessible BSL-learning facilities emphasises this.

As has also been pointed out, while educational inclusion policies have increased deaf children's access to hearing networks, they have made it less likely - even where children have strong bonds with deaf peers at school, and regardless of whether or not BSL is used - that deaf friendships can be maintained in the home environment, because of the low numbers and geographical spread of deaf peers. The implication again is for national and local inclusion policy implementers to be fully aware of this inclusion side-effect, and to facilitate the wherewithal for the building of bridging capital between isolated children and d/Deaf networks – with due regard to the remote rural nature of some of the population.

Model 1(b) illustrates the fact that all deaf children of deaf parents were reported as having problem-free communication in the 'primordial' family domain. This can be seen to correspond with Shepherd and Gallaway's (2003) suggestion that early intervention services should encourage hearing parents to incorporate some of the techniques used by deaf parents into their interactions with their deaf children. Furthermore, none of the deaf children of deaf parents were in the category of those children who had no strong friendships with either deaf or hearing children. However, the model also indicates that some were at least as likely as children of hearing parents to experience some degree of 'visitorship' in hearing networks outside of school. Deaf parents are less likely to be in a position to facilitate the building of bridging capital by taking on leadership and interpreting/communication facilitation roles, but it is not possible to know from the data how far this was a particular disadvantage – and whether or not the deaf parents themselves were experiencing marginalisation.

Arguably, Coleman's (1988) concept of network 'closure' and 'intergenerational closure' could be applied to both 1(a) and 1(b). As noted in chapter 1, there have been criticisms of the excluding nature of both 'phonocentric' hearing networks and those within the Deaf cultural-linguistic community. There

may well be a case for more opportunities to be provided for building of bridging capital between the two networks of parents, in addition to further efforts to address the situations of children who ‘fall between two worlds’. The importance of holistic consideration of the individual situations of children and parents in more complex, multi-culturo-linguistic situations, such as those presented as vignettes in previous chapters, should not be underestimated.

A normative prescription of full ‘membership’ of both d/Deaf and hearing networks for all deaf children is not proposed. It is suggested that the challenge in responding to the diversity of individual habitus, in terms of social capital, seems again to be about providing meaningful choice by: enriching opportunities for bonding in all networks (including bonds with grandparents and other ‘outer’ family members); ensuring that d/Deaf networks are accorded appropriately high status; and facilitating bridging between them. It seems that unit-related mainstream school placements and out-of-school social opportunities, such as those offered by the National Deaf Children’s Society, may be key means of access to d/Deaf networks - with, as might be expected, unit-related placements offering the possibility of simultaneously developing social capital in hearing networks.

It is a tall order to propose that services need to offer a comprehensive package of assessment and resources which would fully reflect the diversity implied by Model 2, and which would aim to facilitate access to both hearing and d/Deaf networks as portrayed in Model 1. The feasibility of perfectly matching the requirements of each individual case, particularly outside of the more densely populated central belt, is undoubtedly problematic. However, it is suggested that conceptualising a child’s interests in this way is likely to encourage policy and practice which would at least consistently aim to meet and overcome such practical barriers; such a holistic mindset would view BSL and Deaf networks as natural strings to a child’s culturo-linguistic bow, within the family and environmental context, rather than as safety nets in the advent of failure.

There are training and resources implications, and the need for a political will to re-frame the way that BSL is conceptualised in the educational domain – clearly as a language rather than as deficit-based type of augmented communication for those with difficulties, as implied in the Languages section of Scotland’s key ‘Curriculum for Excellence’ documentation (The Scottish Government, 2006).

Access to activities

Whatever the linguistic strategies used, it was clear that there were some access issues which could have been addressed relatively easily by providers of social and cultural opportunities to facilitate the fuller participation of children and young people in mainstream social activities, and their access to mainstream cultural activities. It was also evident that hearing parents could end up taking on responsibility for bridging because of the lack of local critical mass of deaf children and the wide range of different types of activities in which a child may wish to participate. This chimes with Young et al.’s holistic conceptualisation of resilience when applied to deaf children: that is, one which takes in the need to build capacity of their family and community as well as their own capacities (Young et al., 2008).

As sport has been shown to have a special potential for increasing self esteem within hearing networks (Shilling, 2003) and as inclusion policies make it increasingly likely that deaf children will wish to access local facilities, it seems that there is a particular need to ensure optimal accessibility of mainstream out-of-school sporting opportunities for deaf children and young people. Issues highlighted include the need to address the size of groups and discriminatory behaviour and attitudes, as well as practical barriers such as alerting deaf competitors to the start of races. Similarly, where access to cultural activities was problematic, relatively straightforward attitudinal and practical changes could have made a difference. The increased provision of subtitles for cinema was a particular plea.

One might hope that anti-discrimination and inclusion legislation and policies will promote increasingly widespread high standard of awareness, adaptations and accessibility developments, so that out-of-school social and cultural opportunities

could become more consistently accessible – whether or not parents are in a position to facilitate the building of bridging capital.

A holistic view of culturo-linguistic networks has implications for the continued provision of opportunities within d/Deaf networks, such as all-deaf sport (including Deaflympics), as well as other Deaf cultural opportunities (Deaf theatre, Deaf art etc).

Transition to independence

The models do not directly address the issue of parental support for their deaf children's transition to independence. However, it is suggested that a 'little linguist' conceptualisation would promote deaf children's own capacity for independence if they are viewed as partners in the process of ongoing assessment and review of flexible choice of linguistic strategies applied to varying communicative environments. In 10 years of working in further and higher education, I regularly witnessed school-leavers who were participating in communication strategy decisions for the first time, and found, more recently, when working on a research study of the experiences of Scottish students, that this was still a not-uncommon situation (Brennan, Grimes, & Thoutenhoofd, 2006:88).

Consistent application of this model would be likely to facilitate the building of social and capital which may well make a difference to the young person's agency in the transition to independence. The implication is that this may increase the likelihood of more parents being inclined to open the padlocked gate of independence sooner rather than later. Young et al.'s (2008) concept of deaf young people's resilience could be applied here, in terms of the inclusion of familial and societal levels of responsibility. A holistic support package would include these levels, and thus also aim to boost parental capacity and confidence to be a 'secure platform', as well as aim to provide high quality resources for the full spectrum of strategies.

Implications for further research

Key premises underpinning the Family Survey support the continued development of further large-scale studies of family life of deaf children. In particular:

- that statistical information from large-scale study has the potential to provide robust, generalisable evidence to inform policy and practice relating to educational achievement, as well as to the socio-cultural and psycho-social prosperity of deaf children;
- that information about family life and out-of-school activity is pertinent to understanding of relevant outcomes;
- that the experiential knowledge and perspectives of parents have epistemological significance; and
- that collaboration with parents in research about family life of deaf children is ethically and epistemologically sound.

It is also suggested that symbolic capital has been shown to be an apt lens through which data relating to family life and out-of school activities of deaf children can be explored: foregrounding language and taking into account the interaction of nuanced, individually-focused experiences with family and socio-cultural networks, as well as environmental influences.

However, among other factors, a higher response rate than that achieved here is needed to enable generalisability. No ‘magic bullet’ is suggested for this, as so many trade-offs are involved when pragmatically balancing the ambitious aims of a collaborative project requiring high response-rates, with practical realities, such as time and funding restrictions. It is therefore conjectured that the trade-off decisions made during this project’s process of research design and implementation, as set out in the methodology chapter, are useful learning points for future similar studies.

For example, major, innovative efforts were made by the collaborative group to ensure that the questionnaire was accessible as possible to all parents. Despite this, there was a bias among the respondent group towards higher socio-economic status. For this and other reasons it may be that it may be more fruitful to consider purposive sampling for future projects, using structured interviews rather than postal questionnaires, as well as longer time scales for discussion and piloting. This would not only aim to address the response rate issue but also problems relating to the lack of control over interpretation of meaning of questions in postal surveys. The use of a control sample within the general population would provide increased robustness by enabling exact comparison of the deaf children's situations with those of hearing children in key areas (such as the quality of communication with individual family members, the extent to which adolescents are allowed to travel independently etc).

While still arguing the benefits of large-scale survey, it has been stressed that the single-perspective/single method nature of the study was limiting in itself. It is suggested that there is need for future large scale family studies, with the capacity to explore permutations of factors through multi-variate analysis, to provide triangulated approaches, which take into account other perspectives (particularly those of young deaf people) and which include qualitative methods, such as observation and in-depth interviews. Such comprehensive studies would go some way to meet the need to provide sufficiently nuanced pictures (including the complex detail of the usage of BSL, manually coded English and English within homes of both deaf and hearing parents), in order to address the complexity of the individual experiences involved.

The concept of habitus could be seen to have value here as a heuristic device for future research: again the centrality of language is key, as well as the pertinence of the synthesis of individual characteristics and experiences with familial and societal influences. It would therefore be fruitful to keep track of developments which may provide more sophisticated tools for analysis of all relevant aspects of symbolic capital. For example Reay (2004) calls for the concept of habitus to be better 'operationalised', and Coleman (1988) suggests the need for the construction

of variables which would clearly embody the interaction between different forms of capital. This kind of creative thinking could be applied to research design relating to Models 1 and 2: for example when using the concept of habitus to explore deaf children's linguistic/capital in relation to their linguistic access strategies.

Although it has been argued that the essentially descriptive and speculative conclusions drawn from findings presented here have heuristic value in themselves, further major limitation of this study have been the lack of link to the measurable outcomes defined as significant in chapter 1 (educational attainment and mental health) as well as the lack of direct comparison with relevant data in the general population (such as data relating to quality of communication within all families). The challenge remains for future large-scale longitudinal studies to be able to include family and out-of-school factors amongst exploration of factors affecting such outcomes.

Despite the constraints of this study, it has, as was hoped, illuminated some substantive issues which appear to be ripe for further study. For example, it is argued that, while there were problematic issues with the construction of the 'learning-related difficulties' variable, there is value in further exploration of the most meaningful standardised way of identifying and isolating such difficulties which impact on the learning of deaf children and young people.

There is also an argument for focused exploration of bonding and bridging issues for deaf children and their families in relation to both deaf and hearing networks. There are a number of possibilities here, but one suggestion is to investigate the impact of the degree of network 'intergenerational closure' on the experiences of deaf parents and hearing parents in supporting their children's access to both socio-cultural groups, and on the deaf child's identity. The fact that other ethnic and socio-cultural networks are relevant for some families would also need to be taken into account and, in particular, it has been suggested that there is a need to explore the implications of current practice regarding use of minority languages between deaf children and members of their families.

Although there was often shown to be a relationship between levels of hearing loss and the experience of deafness-related difficulties, there was persistent diversity in experience which transcended level of deafness. This seems to chime with evidence cited in chapter 1, which raised concerns about the impact of minimal hearing loss levels. However, restricting the focus of analysis to Group 1 children means that the situations of a sizeable group of children with mild, unilateral hearing losses were not explored. It is therefore suggested, as called for by authors of the evidence described, that further research into the situations of those with lesser levels of hearing loss would be illuminating – particularly in light of the fact that some more recently cochlear implanted children may now be functionally within these categories.

A persistent theme in this study has been the implications of the restricted nature of the linguistic spectrum of assessments and resources offered to families, and concerns about evidence that a ‘deficit’ conceptualisation of deafness can underpin and/or perpetuate this restriction, particularly in the context of early diagnosis and early cochlear implantation. In addition to concerns about the need for openness of sign-bilingual choices for socio-cultural development (leading to a ‘best of both worlds’ rather than a ‘falling between two worlds’ scenario), a key assumption has been that some deaf children’s situations, aptitudes and dispositions, lend themselves particularly to the development of a sign language as well as spoken language. It was pointed out in chapter 5 that a comment from a parent seemed to suggest that their primary age cochlear implanted ‘oral’ child was indicating visual-spatial preferences when communicating with deaf peers. It is suggested that more exploration of this kind of situation is needed, in the context of Knoors’ (2007) ‘no exclusion’ principle of assessments and resources, and particularly in relation to early cochlear implantation. Model 2 provides a possible framework for extending this into the choice and utilisation of linguistic strategies by deaf children as they progress through school years. This may also be seen to tie in with Young et al.’s (2008) call for more research into ‘resilience’, in its broadest sense.

Concluding comment

At various points throughout this thesis it has been suggested that major developments, in recent years, have increased the possibility for deaf children to succeed educationally and socially in comparison with their hearing peers. However, it has also been highlighted that it remains a major challenge for research and practice to address the huge disparity among the individual habits of deaf ‘little linguists’. It seems that there is still some way to go in adequately enabling *all* of these diverse children and young people to optimally accumulate, and gain from, linguistic, social and cultural capital, within the complex realities of their family and social lives.

Whilst the focus here has been largely on findings relating to disadvantages experienced by a sizeable minority, it has been stressed that the majority of respondents reported positively on their children’s family situations, across a culturo-linguistic spectrum. For many this meant accumulation of social and cultural capital within the ‘hearing world’. For others, various degrees of inclusion in both deaf and hearing networks was implied. In a spirit of optimism that diversity can be ever-increasingly addressed, I end with an upbeat comment from a respondent hearing parent about their cochlear implanted teenage child, which seems to indicate a young person who has been enabled to accumulate some ‘capital gains’ within both deaf and hearing networks:

‘Now 14 years old with a large circle of friends hearing & deaf. Does a paper round once a week, attends girls brigade weekly, attends deaf church as often as possible. Goes to all deaf centre & XDCS events. Coping well at school. Socialises with friends shops films etc...A well balanced teenager with no hangups about being deaf ‘

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Appendices

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Appendix 1

Family Survey Pilot Questionnaire initial page

(further pages comprised continuation sheets and space for general comments)


achievements of deaf pupils in scotland
Family questionnaire pilot

How long did it take you to complete the questionnaire?

Please give any *specific* feedback (there is space for general comments on page 3):

| Page No. | Question No. | Comments |
|----------|--------------|----------|
| | | |

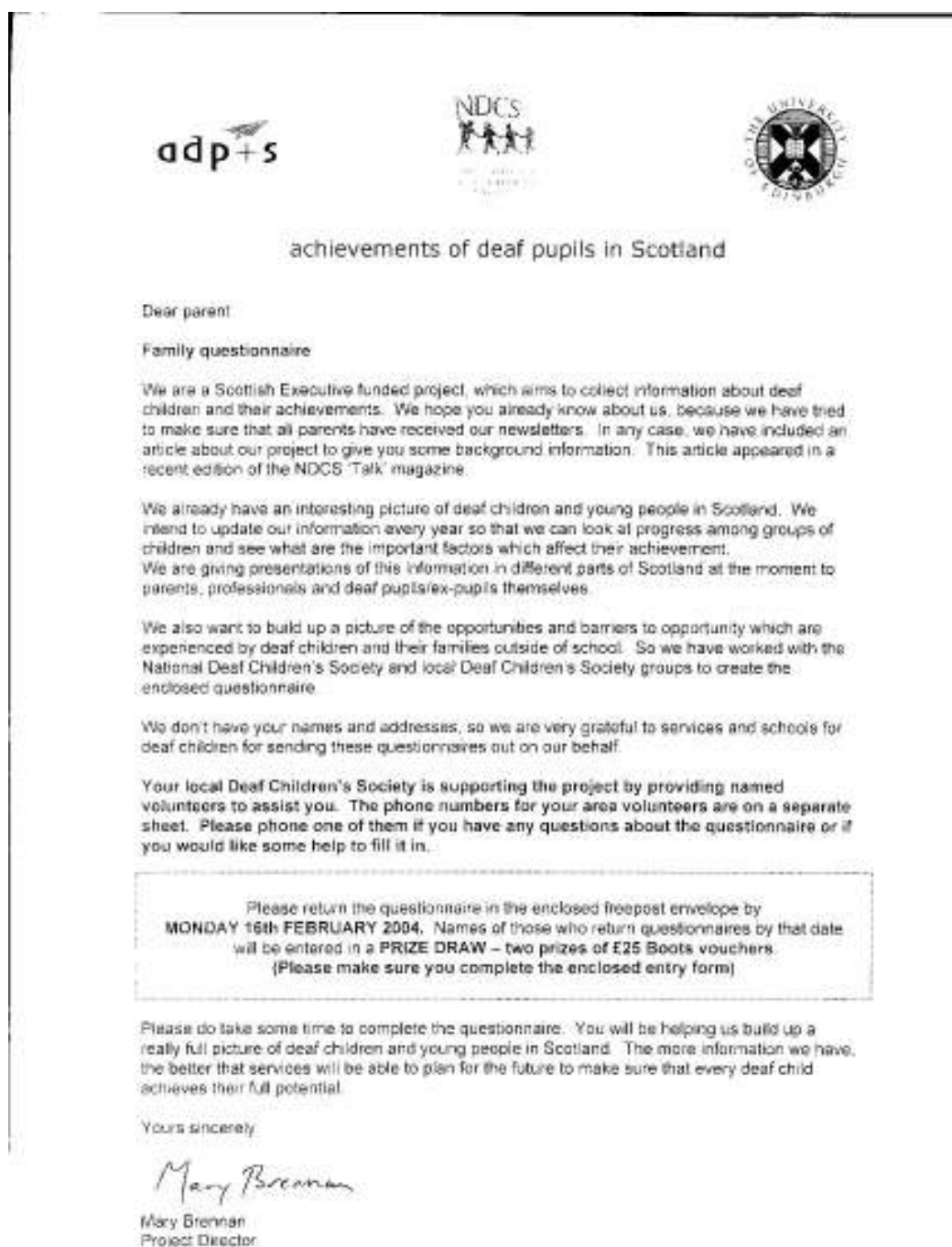
Please continue overleaf if necessary,...

1

Appendix 2

Survey Pack Contents

a) Covering letter



b) Offer to provide more information in other languages
(second page offered two more languages)





Would you like a BSL video tape of the letter from Mary (Gretman)?
If yes, please write your name and address here:

Now post this paper back to us in the enclosed envelope (you do not need a stamp).



এই প্রকল্পটি স্কটিশ এডভান্সডেডিটিজ এর অর্থিক সহায়তায় পরিচালিত। দি এডভান্সডেডেডিটিজ অফ স্কটিশ নিউকম্বার ইন্ডাস্ট্রিজ প্রকল্পের শীর্ষক। এই প্রকল্পটি শিক্ষক/শিক্ষিকা ও পিতামাতার নিকট থেকে স্কটিশের এর সকল বর্ষের শিশুদের বিষয়ে তথ্য সংগ্রহ করছে। এই তথ্যগুলো স্কটিশের বর্ষের শিশুদের বিষয়ে জাতীয় ও স্থানীয় পর্যায়ে শিক্ষার উন্নয়নে ব্যবহৃত হবে।

আপনি যদি এই তথ্যটি আপনার নিজের জীবন পূরণ করার ক্ষেত্রে সহায়তা পেতে চান তাহলে দয়া করে এই বক্সটিতে ☐ চিহ্ন দিন।

এখানে আপনার নাম ও ঠিকানা লিখুন: _____

টেলিফোন নম্বর: _____

এবার করা করে সাথে সাথে আপনি আরও প্রকল্পটি জানাবেন নিকট যেকোন পরামর্শ (স্টাম্প এর নবায়ন নেই)



這份卷由“蘇格蘭聾人學生成就計劃”(The Achievements of Deaf Pupils in Scotland project)發出。這計劃由蘇格蘭行政院撥款推行。現正從老師及家長搜集所有在蘇格蘭聾人兒童的資料。而資料將會用來協助全國性與本地有關聾人兒童教育的決策。

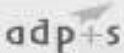
如果你願意知悉以你自己的語言填寫該問卷，請於該卷內劃上“✓”號。 ☐

請在以下空白處寫上你的姓名及地址： _____


電話： _____

現在請將問卷以附上之信封寄回給我們（無需貼上郵票）。

c) Invitation to contact a local volunteer



achievements of deaf pupils in Scotland



NDCS
THE NATIONAL
DEAF CHILDREN'S
SOCIETY

Do you have any questions about the Family Questionnaire?
If so, find a local contact and get in touch with them
(**John MacGillivray**, Family Officer for NDCS, is named in areas where there is only one other volunteer)
If you can't contact one of your local people, try one of the others.

Borders

John MacGillivray
[redacted]
Tel: [redacted]
Email: [redacted]

John MacGillivray
[redacted]
Tel: [redacted]
Fax: [redacted]
Email: [redacted]

Central Scotland

John MacGillivray
[redacted]
Tel: [redacted] mobile: [redacted]
Email: [redacted]

John MacGillivray
[redacted]
Tel: [redacted]
Email: [redacted]

John MacGillivray
[redacted]
Tel: [redacted]
Email: [redacted]

John MacGillivray
[redacted]
Tel: [redacted]
Work: [redacted]
mobile: [redacted]
Email: [redacted]

Dumfries and Galloway

John MacGillivray
[redacted]
Tel: [redacted]
mobile: [redacted]

John MacGillivray
[redacted]
Tel: [redacted]
Fax: [redacted]
Email: [redacted]

Dunbartonshire/West of Scotland

John MacGillivray
[redacted]
(day-time only) Tel: [redacted]
Email: [redacted]

John MacGillivray
[redacted]
Text daytime: [redacted]
Text evening: [redacted]
mobile text: [redacted]

John MacGillivray
[redacted]
Tel: [redacted]
Email: [redacted]

John MacGillivray
[redacted]
(day-time only) Tel: [redacted]
Email: [redacted]

Frances Dolan
[redacted]
(day-time only) Tel: [redacted]
Email: [redacted]

PTO

The Achievements of Deaf Pupils in Scotland

by Marian Grimes, Research Associate

The Achievements of Deaf Pupils in Scotland (ADPS) project is funded by the Scottish Executive to collect and share information about the achievements of deaf pupils (FALK 157).

Hopefully, most parents of deaf children in Scotland will know about us by now because we have tried hard to make sure that we keep families up-to-date with our progress. We have sent newsletters out via schools and services, held open days and kept in touch with NDCS Scotland and local Deaf Children's Societies (DCSs) across the country.

The ADPS Scottish survey

Part of the work of the ADPS project is to collect detailed information on deaf pupils and enter this into a computer database, which can be updated on a yearly basis. We worked with parents, professionals and deaf people to develop questionnaires for teachers to complete on each child at a school or unit for deaf children, and each one visited twice a year or more by a visiting teacher of the deaf (Group A pupils). More limited information was collected on pupils visited once a year or less (Group B pupils). Separate pre-school questionnaires were completed for each pre-school child known to services. (The information is confidential and it will not be possible to identify individual children from published results.)

A total of 39.4% of the school questionnaires and 88% of the pre-school questionnaires were returned for the 2000/1 academic year. Many thanks to teachers and other staff – such as speech and language therapists and audiologists – who filled them in.

What will the information tell us?

A full report is being prepared which will include detailed information about the 2000/1 academic year, including: numbers; hearing loss type and levels; levels of physical and learning disabilities. This account will also provide the most detailed information to date on the attainments of deaf pupils, such as the levels achieved within the 5-14 framework, Standard Grades and Highers as well as specialist qualifications in BSL, Lip-Reading and Deaf Studies. In the meantime we present three simple examples of our findings for 2000/1.

Numbers of deaf children in Scotland

There were 2,281 children and young people known to Scottish deaf education services in 2000/1. Of these, 211 were pre-school children and 2,070 attended school. 1,416 of the

school pupils were in Group A and 654 were in Group B.

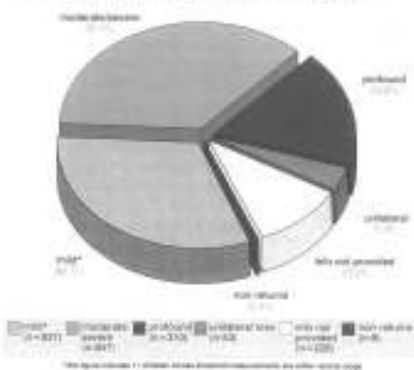
Figure 1: Deaf pre-school children and school pupils known to deaf education services in Scotland 2000/1 (n=2,281)



Hearing loss levels of deaf children in Scotland

Of the 2,281 children, 37% had a mild hearing loss; 37% had a moderate or severe loss; 14% had a profound loss, and 2% had a hearing loss in one ear only (unilateral). Information about hearing loss levels was not provided for 11% of the total group.

Figure 2: Deaf pre-school children and school pupils in Scotland by hearing loss level 2000/1 (n=2,281)



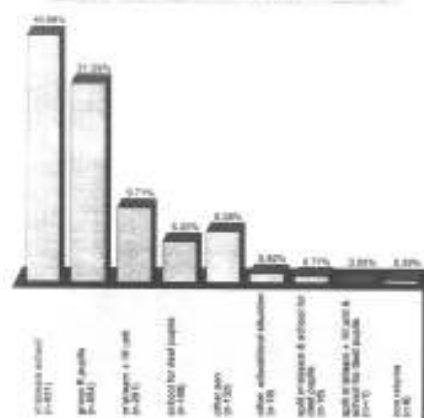
(cont)

Scottish education

School placements of deaf pupils in Scotland

In recent years an increasing number of deaf children have been educated in mainstream schools. The current pattern of placements is shown in this diagram. Currently we do not have specific placement details on Group B pupils, but it can be assumed that most will be in mainstream.

Figure 3: Deaf school profile in Scotland by type of placement 2000/1 (n=2,078)



Future plans


We are aware that raw figures can be misleading, so a key part of the ongoing research is to examine those factors that may affect the levels of attainment. However, it would be inappropriate to draw too many conclusions from just one year's figures, so we will be updating the database on a yearly basis. We will need to look at results over several years to identify which factors may have significant impact on progress.

We are working closely with Scottish DCSs to devise a questionnaire for parents so that we can collect home and family information to add to the database. We hope that all the information will be helpful to pupils and families themselves, as well as to professionals and policy-makers. If you receive one of our questionnaires in Scotland, please do complete it and return it to us - local DCS volunteers will assist if this is helpful. Fife DCS and local professionals are also working with us to pilot a separate ProDeaf (profiling deaf children) database. TALK will bring you more on this exciting project at a later date.


Please do get in touch if you have any comments or questions about what we are doing. We plan to visit as many DCSs throughout Scotland as we can to present our findings - let us know if you would like us to visit your area. Contact:

Marian Grimes, Research Associate, ADPS Project
 Simon Laurie House
 University of Edinburgh
 Holyrood Road
 Edinburgh EH8 8AQ
 Tel: 0131 651 6462 (voice)/0131 651 6470 (fax)
 Fax: 0131 651 6469
 E-mail: deaf@achieve@ed.ac.uk

e) Prize draw form



PRIZE DRAW



If you complete this questionnaire and return it to us by **16th February**
you can enter our **PRIZE DRAW**

Prizes: 2 Boots vouchers of £25 each

Fill in your name and address here if you want to be included in the draw:

Name

Address

Postcode

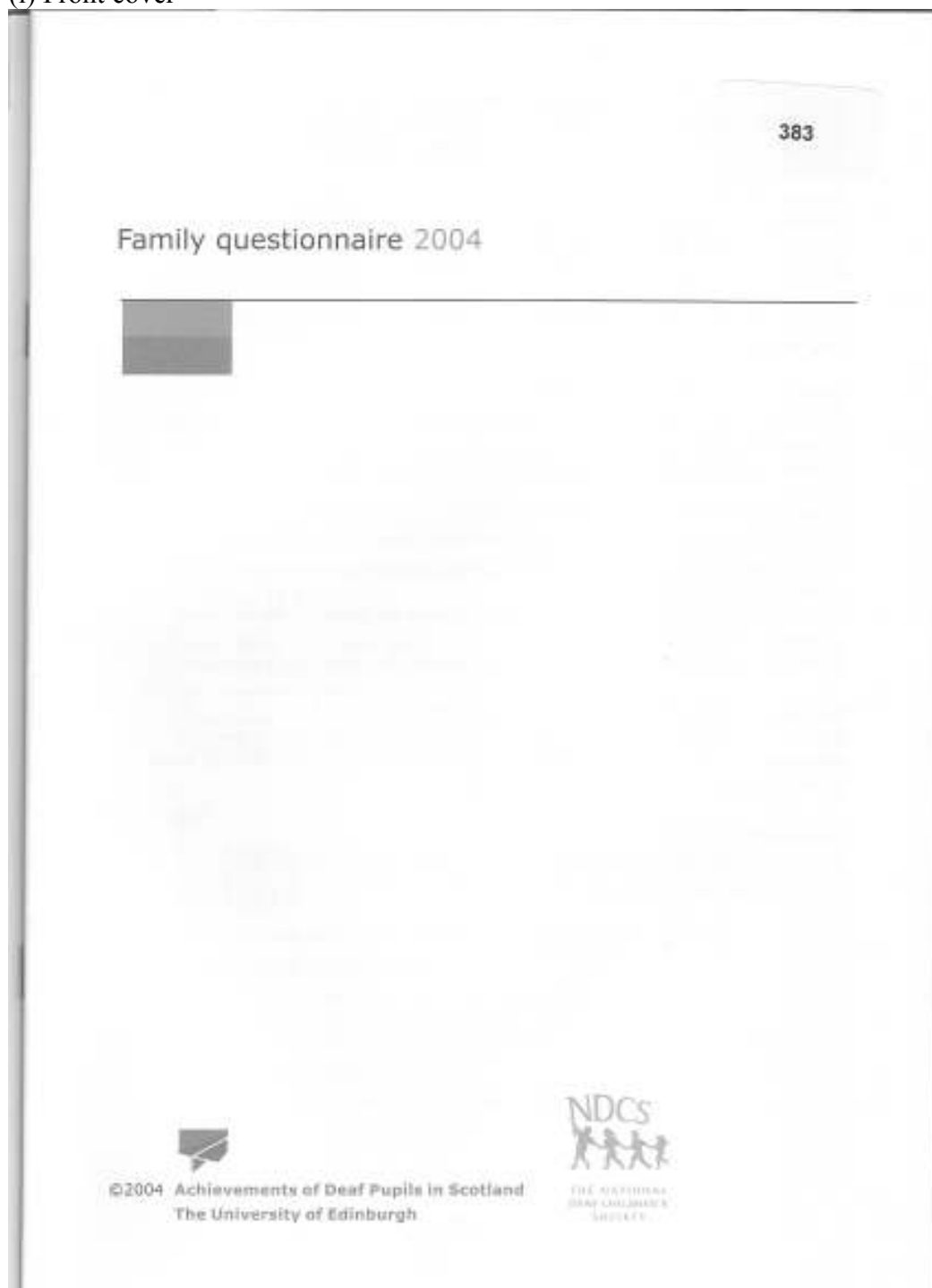
Now, return this slip in the same envelope as the questionnaire
(please do not put inside the questionnaire)

The winning slip will be drawn on *Friday 20th February 2004*
by the Chair of the East of Scotland Deaf Children's Society

g) Family Survey Questionnaire – selected pages

These selected pages are shown here to show the questions relating to personal details and to illustrate the format and presentation of the survey instrument. The texts of questions used in this thesis are set out in individual appendices for easy reference.

(i) Front cover



(ii) Information page

Please complete and return this confidential questionnaire about your deaf child.
You will be helping us provide accurate information about deaf children in Scotland.
Your questionnaire will inform national and local decisions about education.

Confidentiality

The information provided is completely confidential and no children or families will be identified in any published materials. ADPS is securely within the Data Protection Act regulations for the safekeeping of information on the database.

Even if you do not wish to give the name of your child, please do still complete the questionnaire.

Words we use in the questionnaire

- 1 We use the term child all the way through the form, no matter what the age of your daughter or son.
- 2 When we talk about home, we are talking about the main place of residence of your deaf child.
- 3 We realise that not everyone completing this form will be the birth parents of the deaf child. For example you may be a step-parent or a foster parent, but for simplicity we use the terms parents, mother and father to refer to all parents/carers with parental responsibility for the child.
- 4 Similarly, when we refer to brothers and sisters we are including step and foster brothers and sisters etc.
- 5 The word deaf is used to refer to all levels of hearing loss, from mild to profound.

Questions on ethnic background, language and faith

We have included these questions because we believe it is important to take them into account when we are producing statistics. We have taken advice from the Minority Ethnic Learning Disability Initiative (MELDI) in Scotland.

Completed questionnaires

Please return your completed questionnaire in the freepost envelope provided.

| | |
|--|---|
| <p>Section 1 Personal details</p> <p>Identity of the person who is completing this form</p> <p>Please tick one of the following boxes to show what your relationship is to the deaf child in the family.</p> <p><input type="checkbox"/> Mother</p> <p><input type="checkbox"/> Father</p> <p><input type="checkbox"/> Other (please give details)</p> | <p>7 What is the faith/religion, if any, of your deaf child?</p> |
| <p>Part 1 Identity and social context of the deaf child</p> <p>1 Name or initials of deaf child _____</p> <p>2 Date of birth ____ / ____ / ____</p> <p>3 Gender</p> <p><input type="checkbox"/> Male</p> <p><input type="checkbox"/> Female</p> <p>4 Home postcode _____</p> <p>5 Please describe the ethnic background of your deaf child. Use whichever term or terms you feel most comfortable with. You may wish to give a specific race or group, such as African, Gypsy Traveller, Irish, Pakistani. You may wish to use a broader term, such as Scottish, White Scottish, Asian Scottish, Black Scottish, etc.</p> <p>6 What is the first language of your deaf child, eg English, BSL, Arabic, Gaelic, Punjabi, etc? If your deaf child is bilingual, please name both languages.</p> | <p>Part 2 General family information</p> <p>1 Please tick a box to show how many hearing parents presently live with your deaf child.</p> <p><input type="checkbox"/> None</p> <p><input type="checkbox"/> 1</p> <p><input type="checkbox"/> 2</p> <p>2 Please tick a box to show how many deaf parents presently live with your deaf child.</p> <p><input type="checkbox"/> None</p> <p><input type="checkbox"/> 1</p> <p><input type="checkbox"/> 2</p> <p>3 Does your child split their time between two separate homes? (eg if you are divorced/separated)</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p>4 How many hearing brothers and sisters live at home with your deaf child? Number of brothers/sisters _____</p> <p>5 How many deaf brothers and sisters live at home with your deaf child? Number of brothers/sisters _____</p> <p>6 Please give the ages of all your children at home, including your deaf child, starting with the oldest.</p> <p>Oldest child at home: _____</p> <p>Next oldest child at home _____</p> <p>Next oldest child at home _____</p> <p>Next oldest child at home _____</p> <p>Next oldest child at home _____</p> <p>Next oldest child at home _____</p> <p>Next oldest child at home _____</p> |

(iii) Section 1, Part 3

page 4

| Part 3 Information about your deaf child | |
|---|---|
| <p>1a When did your child become deaf? (Please tick one box)</p> <p><input type="checkbox"/> During mother's pregnancy/genetic</p> <p><input type="checkbox"/> Between birth and 6 weeks</p> <p><input type="checkbox"/> Sometime before 6 weeks (unsure when)</p> <p><input type="checkbox"/> 6 weeks-6 months</p> <p><input type="checkbox"/> 7-11 months</p> <p><input type="checkbox"/> 12-24 months</p> <p><input type="checkbox"/> Over 2 years</p> <p><input type="checkbox"/> Not known/unsure</p> | <p>Level of condition</p> <p><input type="checkbox"/> Mild</p> <p><input type="checkbox"/> Moderate</p> <p><input type="checkbox"/> Severe</p> <p>Diagnosed by (name of profession eg paediatrician, ophthalmologist etc)</p> |
| <p>1b If known, at what exact age did your child become deaf? (yy/mm) ____ / ____</p> | <p>Name of condition (2)</p> <p><input type="checkbox"/> Not applicable</p> <p><input type="checkbox"/> Not known</p> |
| <p>2 When was your child diagnosed as deaf? (please give the age of the child or date of diagnosis)</p> <p><input type="checkbox"/> Age at diagnosis (yy/mm) ____ / ____</p> <p>or</p> <p><input type="checkbox"/> if neonatal (days) ____</p> <p>or</p> <p><input type="checkbox"/> Date of diagnosis ____ / ____ / ____</p> <p><input type="checkbox"/> Not known/unsure</p> | <p>Level of condition</p> <p><input type="checkbox"/> Mild</p> <p><input type="checkbox"/> Moderate</p> <p><input type="checkbox"/> Severe</p> <p>Diagnosed by (name of profession eg paediatrician, ophthalmologist etc)</p> |
| <p>3 What was the cause of your child's deafness?</p> <p><input type="checkbox"/> Not known, even after investigation</p> <p><input type="checkbox"/> Not known, not investigated</p> | <p>4b Diagnosed medical conditions/physical disabilities</p> <p>Name of condition (1)</p> <p><input type="checkbox"/> Not applicable</p> <p><input type="checkbox"/> Not known</p> |
| <p>4 Please list any diagnosed visual impairments, medical conditions and specific learning difficulties experienced by your deaf child under 4a-d:</p> | <p>Level of condition</p> <p><input type="checkbox"/> Mild</p> <p><input type="checkbox"/> Moderate</p> <p><input type="checkbox"/> Severe</p> |
| <p>4a Diagnosed visual impairments</p> <p>Name of condition (1)</p> <p><input type="checkbox"/> Not applicable</p> <p><input type="checkbox"/> Not known</p> <p>(continued in the next column)</p> | <p>Diagnosed by (name of profession eg paediatrician, ophthalmologist etc)</p> |

| | |
|--|---|
| <p>Name of condition (2)</p> <p><input type="checkbox"/> Not applicable <input type="checkbox"/> Not known</p> <p>Level of condition</p> <p><input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe</p> <p>Diagnosed by (name of profession eg paediatrician, ophthalmologist etc)</p> | <p>Level of condition</p> <p><input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe</p> <p>Diagnosed by (name of profession eg paediatrician, ophthalmologist etc)</p> <p>4d Any comments about physical and learning disabilities?</p> |
| <p>4c Diagnosed specific learning difficulty (eg autistic spectrum disorder; asperger's syndrome; attention deficit hyperactivity syndrome; dyslexia; social emotional and behavioural difficulties; dyspraxia)</p> | <p>Part 4 Information about language and communication in the home</p> |
| <p>Name of condition (1)</p> <p><input type="checkbox"/> Not applicable <input type="checkbox"/> Not known</p> <p>Level of condition</p> <p><input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe</p> <p>Diagnosed by (name of profession eg paediatrician, ophthalmologist etc)</p> | <p>For all of the following questions we are referring to languages such as English (spoken or Sign Supported English), Gaelic, BSL, Urdu, etc.</p> <p>1a What is the main language used at home within the family? If the family uses two languages equally, please write them both here.</p> |
| <p>Name of condition (2)</p> <p><input type="checkbox"/> Not applicable <input type="checkbox"/> Not known</p> <p>(continued in the next column)</p> | <p>1b What other languages are used at home within the family?</p> |

(v) Section 1, Part 4 (cont)

page 6

| | |
|--|---|
| <p>2 What language(s) do you (mother) use with your deaf child? This can be completed directly by the person concerned or by the partner on their behalf.</p> | <p>Any comments?</p> |
| <p>Any comments?</p> | <p>6 Do you have any comments about languages used between other family members and your deaf child?</p> |
| <p>3 What language(s) do you (father) use with your deaf child? This can be completed directly by the person concerned or by the partner on their behalf.</p> | |
| <p>Any comments?</p> | |
| <p>4 What language(s) do any brothers and sisters use with your deaf child?</p> | |
| <p><input type="checkbox"/> Not applicable</p> | <p>We would like to share the information in Section 1 in confidence with the teacher(s) of deaf children who work(s) with your deaf child. This is to double-check that these basic details are correctly recorded in your child's file at school/visiting service. It will never be possible to identify your child or family from any information we publish.</p> |
| <p>Any comments?</p> | <p>Please tick one of the boxes to let us know whether we can share this information or not:</p> |
| <p>5 What language(s) do any grandparents use with your deaf child?</p> | <p><input type="checkbox"/> Section 1 information can be shared with my child's teacher(s) of deaf children.*</p> |
| <p><input type="checkbox"/> Not applicable</p> | <p>or</p> |
| <p>(continued in the next column)</p> | <p><input type="checkbox"/> Do not share Section 1 information with my child's teacher(s) of deaf children.</p> |
| | <p>* Please make sure you have completed questions 1 and 2 (page 3).</p> |

Appendix 3

Questions relating to communication with individual family members

Section 1, part 4

(NB most of the answers to this question were factual details of languages used, but there were some responses about quality of communication within open comments sections)

2. What languages do you (mother) use with your deaf child? This can be completed directly by the person concerned or by the partner on their behalf.

Any comments

3. What languages do you (father) use with your deaf child? This can be completed directly by the person concerned or by the partner on their behalf.

Any comments

4. What languages do any brothers and sisters use with your deaf child?

Any comments

5. What languages do any grandparents use with your deaf child?

Any comments

6 Do you have any comments about languages used between other family members and your deaf child?

Section 2

1. (referred to in this thesis as the 'Quality of Communication Question')

On a scale from 1 (very well) to 5 (not well at all), how well does your deaf child communicate with each family member? Please circle one number for each line.

(n/a = not applicable)

| | 1 | 2 | 3 | 4 | 5 | n/a |
|-----------------------------|---|---|---|---|---|--------------------------|
| Mother | | | | | | <input type="checkbox"/> |
| Father | | | | | | <input type="checkbox"/> |
| Brothers and sisters | | | | | | |
| Other adults | | | | | | |
| (eg uncle, grandparent) | | | | | | <input type="checkbox"/> |
| Other children/young people | | | | | | |
| (eg cousin, niece) | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |

Any other comments about communication with family?

Section 3, part 8

1. (referred to in this thesis as the 'Discussion Question')

On a scale from 1 (always) to 3 (never), how often are you able to do these things with your deaf child:

| | 1 | 2 | 3 | n/a |
|---|---|---|---|--------------------------|
| Discuss with them the day's events (eg at school/nursery) | | | | <input type="checkbox"/> |
| Support them in doing their homework | | | | <input type="checkbox"/> |
| Discuss with them their own interests | | | | <input type="checkbox"/> |

Are there any difficulties relating to deafness which prevent any of these interactions?

- ☐ yes
☐ no

If yes, please give details:

Appendix 4

All data in this appendix relates to the following group of cases: Group 1; school-age; hearing parents; no learning disabilities; severely/profoundly deaf or cochlear implanted.

Two sub-groups among these cases have been identified:

Sub group A: High level of communication reported between deaf child and mother(‘communicates very well’) and no difficulties relating to deafness reported in key types of discussions between deaf child and respondent parent.

Sub-group B: Communication with mother reported as less than ‘very well’ and difficulties relating to deafness were reported in key types of discussions between deaf child and respondent parent.

Data on the following variables is listed for each group below: gender; ethnicity; child’s first language; onset of deafness; cause of deafness; main language(s) used at home; languages used by mother; school placement; household social class; mother’s highest level of qualification

Sub-group A (High level of communication reported between deaf child and mother [‘communicates very well’] and no difficulties relating to deafness reported in key types of discussions between deaf child and respondent parent).

Sub-group A: Gender

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|--------------|-----------|---------|---------------|--------------------|
| Valid female | 29 | 50.0 | 50.0 | 50.0 |
| male | 29 | 50.0 | 50.0 | 100.0 |
| Total | 58 | 100.0 | 100.0 | |

Sub-group A: Ethnicity

| | Frequency | Valid Percent |
|-----------------|-----------|---------------|
| Valid Scottish | 18 | 33.3 |
| White Scottish | 26 | 48.1 |
| Scottish/Thai | * | * |
| British | * | * |
| White British | * | * |
| White English | * | * |
| Pakistani | * | * |
| Danish | * | * |
| Total | 54 | 100.0 |
| Missing missing | 4 | |
| Total | 58 | |

* less than 5 cases (anonymised as some information potentially sensitive)

Sub-group A: child's 1st lang coded2

| | Frequency | Valid Percent |
|----------------------------------|-----------|---------------|
| Valid English/Scottish | 44 | 75.9 |
| Eng + at least one other sp lang | 1 | 1.7 |
| BSL or BSL + ISL | 2 | 3.4 |
| BSL + Eng | 11 | 19.0 |
| Total | 58 | 100.0 |

Sub-group A: Child's 1st lang coded (more detail)

| | Frequency | Valid Percent |
|--|-----------|---------------|
| Valid English | 40 | 69.0 |
| Scottish | 1 | 1.7 |
| Manually Coded English | 2 | 3.4 |
| 'Total Communication' | 1 | 1.7 |
| BSL or BSL and ISL | 2 | 3.4 |
| English and BSL | 11 | 19.0 |
| English and at least one other spoken language | 1 | 1.7 |
| Total | 58 | 100.0 |

Sub-group A: Onset of deafness

| | Frequency | Valid Percent |
|---|-----------|---------------|
| Valid during mother's pregnancy/genetic | 27 | 46.6 |
| between birth and 6 weeks | 8 | 13.8 |
| sometime before 6 weeks | 1 | 1.7 |
| 6 weeks - 6 months | 1 | 1.7 |
| 7-11 months | 1 | 1.7 |
| 12-24 months | 2 | 3.4 |
| over 2 years | 7 | 12.1 |
| not sure / not known (x) | 11 | 19.0 |
| Total | 58 | 100.0 |

Sub-group A: cause of deafness

| | Valid Percent |
|-----------------------------|---------------|
| Valid | 53.4 |
| ?perilymph fistula | * |
| Bone function | * |
| Cytomegalo Virus | * |
| genetic | * |
| Genetic | 12.1 |
| Maybe under birth | * |
| Meningitis | * |
| MMR Reported vaccine damage | * |
| MR Vaccine | * |
| Nerve damage | * |

| | |
|--|-------|
| Neurosensory loss | * |
| Ototoxic medication | * |
| Pollop's | * |
| Premature/medication for other complications | * |
| Presumed genetic | * |
| Think Genetic- plan to have DNA tests to establish cause | * |
| Think Genetic | * |
| Told it was recessive genes | * |
| Unknown, cochlear not developed | * |
| Vancrmicin(anti biotic) Chemo treatment | * |
| Waadenburgh Syndrome | * |
| Total | 100.0 |

* less than 5 cases (anonymised as some information potentially sensitive)

Sub-group A: main language(s) used at home

| | Frequency | Valid Percent | Cumulative Percent |
|--|-----------|---------------|--------------------|
| Valid English | 36 | 63 | 63.2 |
| Manually Coded English | 7 | 12 | 75.4 |
| English and BSL | 10 | 18 | 93.0 |
| English and at least one other spoken language | 4 | 7 | |
| Total | 57 | 100.0 | 100.0 |
| Missing System | 1 | | |
| Total | 58 | | |

Sub-group A: langs used by mother coded

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------------------------|-----------|---------|---------------|--------------------|
| Valid SSE & BSL & English | 4 | 6.9 | 6.9 | 6.9 |
| BSL & English | 3 | 5.2 | 5.2 | 12.1 |
| English | 39 | 67.2 | 67.2 | 79.3 |
| SSE | 2 | 3.4 | 3.4 | 82.8 |
| English & limited signing | 7 | 12.1 | 12.1 | 94.8 |
| English & gestures | 2 | 3.4 | 3.4 | 98.3 |
| no response | 1 | 1.7 | 1.7 | 100.0 |
| Total | 58 | 100.0 | 100.0 | |

Sub-group A: Langs used by mother coded2

| | Frequency | Percent | Valid Percent | Cumulative Percent |
|----------------------------|-----------|---------|---------------|--------------------|
| Valid English/Scottish | 50 | 86.2 | 87.7 | 87.7 |
| BSL (or BSL+ISL) + English | 7 | 12.1 | 12.3 | 100.0 |
| Total | 57 | 98.3 | 100.0 | |
| Missing no response | 1 | 1.7 | | |
| Total | 58 | 100.0 | | |

Sub-group A: current school placement

| | | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------|---|-----------|---------|---------------|--------------------|
| Valid | mainstream school with in-class specialist support | 32 | 55.2 | 55.2 | 55.2 |
| | mainstream school with no in-class specialist support | 4 | 6.9 | 6.9 | 62.1 |
| | mainstream school with HI/deaf unit | 18 | 31.0 | 31.0 | 93.1 |
| | school for deaf children | 4 | 6.9 | 6.9 | 100.0 |
| | Total | 58 | 100.0 | 100.0 | |

Sub-group A: Household's social class

| | | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------|---------------------------|-----------|---------|---------------|--------------------|
| Valid | managerial & professional | 26 | 44.8 | 44.8 | 44.8 |
| | intermediate | 19 | 32.8 | 32.8 | 77.6 |
| | working | 8 | 13.8 | 13.8 | 91.4 |
| | unclassified | 5 | 8.6 | 8.6 | 100.0 |
| | Total | 58 | 100.0 | 100.0 | |

Sub-group A: Mother's highest qualification

| | | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|--|-----------|---------|---------------|--------------------|
| Valid | No qualifications | 4 | 6.9 | 7.1 | 7.1 |
| | CSEs, O-Grades/Levels, Standard Grades, SCOTVEC modules etc. | 14 | 24.1 | 25.0 | 32.1 |
| | Highers or A-Levels | 8 | 13.8 | 14.3 | 46.4 |
| | HNC, HND, RGN, teaching diploma etc. | 11 | 19.0 | 19.6 | 66.1 |
| | Degree or Higher Degree | 18 | 31.0 | 32.1 | 98.2 |
| | Other (specify) | 1 | 1.7 | 1.8 | 100.0 |
| | Total | 56 | 96.6 | 100.0 | |
| Missing | no response | 2 | 3.4 | | |
| Total | | 58 | 100.0 | | |

Sub-Group B (Communication with mother reported as less than ‘very well’ and difficulties relating to deafness were reported in key types of discussions between deaf child and respondent parent).

Sub-group B: Gender

| | Frequency | Valid Percent |
|--------------|-----------|---------------|
| Valid female | 6 | 40.0 |
| male | 9 | 60.0 |
| Total | 15 | 100.0 |

Sub-group B: Ethnicity

| | Frequency | Valid Percent |
|----------------|-----------|---------------|
| Valid Scottish | * | * |
| White Scottish | 6 | 40.0 |
| British | * | * |
| Pakistani | * | * |
| Iraqi | * | * |
| Total | 15 | 100.0 |

* less than 5 cases (anonymised as some information potentially sensitive)

Sub-group B: Child's 1st lang coded

| | Frequency | Valid Percent |
|---|-----------|---------------|
| Valid English | 11 | 73.3 |
| BSL or BSL and ISL | 1 | 6.7 |
| At least one spoken language other than English | 2 | 13.3 |
| English and at least one other spoken language | 1 | 6.7 |
| Total | 15 | 100.0 |

Sub-group B: child's 1st lang coded2

| | Frequency | Valid Percent |
|-------------------------------------|-----------|---------------|
| Valid English/Scottish | 11 | 73.3 |
| Eng + at least one other sp lang | 1 | 6.7 |
| at least one sp lang other than Eng | 2 | 13.3 |
| BSL or BSL + ISL | 1 | 6.7 |
| Total | 15 | 100.0 |

Sub-group B: Onset of deafness

| | Frequency | Valid Percent |
|---|-----------|---------------|
| Valid during mother's pregnancy/genetic | 7 | 46.7 |
| between birth and 6 weeks | 1 | 6.7 |
| sometime before 6 weeks | 1 | 6.7 |
| 6 weeks - 6 months | 2 | 13.3 |
| over 2 years | 1 | 6.7 |
| not sure / not known (x) | 3 | 20.0 |
| Total | 15 | 100.0 |

Sub-group B: cause of deafness

| | Frequency | Valid Percent |
|---------------------------|-----------|---------------|
| Valid | 10 | 66.7 |
| Asphyxiation at birth | * | * |
| Connexin 26 gene | * | * |
| Genetic | * | * |
| No cause/could be genetic | * | * |
| Total | 15 | 100.0 |

* less than 5 cases (anonymised as some information potentially sensitive)

Sub-group B: main language(s) used at home

| | Frequency | Valid Percent |
|---|-----------|---------------|
| Valid English | 9 | 60.0 |
| Manually Coded English | 2 | 13.3 |
| English and BSL | 2 | 13.3 |
| At least one spoken language other than English | 1 | 6.7 |
| English and gestures | 1 | 6.7 |
| Total | 15 | 100.0 |

Sub-group B: main lang at home coded2

| | Frequency | Valid Percent |
|-------------------------------------|-----------|---------------|
| Valid English/Scottish | 12 | 80.0 |
| at least one sp lang other than Eng | 1 | 6.7 |
| BSL + Eng | 2 | 13.3 |
| Total | 15 | 100.0 |

Sub-group B: langs used by mother coded

| | | Frequency | Valid Percent |
|-------|---------------------------|-----------|---------------|
| Valid | BSL & English | * | * |
| | English | 7 | 46.7 |
| | SSE & English | * | * |
| | English & limited signing | * | * |
| | English & gestures | * | * |
| | Urdu | * | * |
| | no response | * | * |
| | Total | 15 | 100.0 |

* less than 5 cases (anonymised as some information potentially sensitive)

Sub-group B: Langs used by mother coded2

| | | Frequency | Valid Percent |
|---------|---|-----------|---------------|
| Valid | English/Scottish | 12 | 85.7 |
| | At least one spoken language other than English | 1 | 7.1 |
| | BSL (or BSL+ISL) + English | 1 | 7.1 |
| | Total | 14 | 100.0 |
| Missing | no response | 1 | |
| Total | | 15 | |

Sub-group B: current placement

| | | Frequency | Valid Percent |
|---------|--|-----------|---------------|
| Valid | mainstream school with in-class specialist support | 7 | 50.0 |
| | mainstream school with HI/deaf unit | 5 | 35.7 |
| | school for deaf children | 2 | 14.3 |
| | Total | 14 | 100.0 |
| Missing | System | 1 | |
| Total | | 15 | |

Sub-group B: Household's social class

| | | Frequency | Valid Percent |
|-------|---------------------------|-----------|---------------|
| Valid | managerial & professional | 9 | 60.0 |
| | intermediate | 2 | 13.3 |
| | unclassified | 4 | 26.7 |
| | Total | 15 | 100.0 |

Sub-group B: Mother's highest qualification

| | | Frequency | Valid Percent |
|---------|--|-----------|---------------|
| Valid | CSEs, O-Grades/Levels, Standard Grades, SCOTVEC modules etc. | 2 | 14.3 |
| | Highers or A-Levels | 4 | 28.6 |
| | HNC, HND, RGN, teaching diploma etc. | 3 | 21.4 |
| | Degree or Higher Degree | 3 | 21.4 |
| | Other (specify) | 2 | 14.3 |
| | Total | 14 | 100.0 |
| Missing | no response | 1 | |
| Total | | 15 | |

Sub-group B: Local Authority

| | | Frequency | Valid Percent |
|-------|-------|-----------|---------------|
| Valid | *30 | 1 | 6.7 |
| | *00 | 2 | 13.3 |
| | *10 | 1 | 6.7 |
| | *20 | 1 | 6.7 |
| | **30 | 1 | 6.7 |
| | *31 | 1 | 6.7 |
| | *50 | 1 | 6.7 |
| | *61 | 1 | 6.7 |
| | *63 | 1 | 6.7 |
| | *64 | 2 | 13.3 |
| | **00 | 1 | 6.7 |
| | *23 | 1 | 6.7 |
| | **00 | 1 | 6.7 |
| | Total | 15 | 100.0 |

Appendix 5

a) Difficulties with discursive interactions: CI; group 1; not preschool; no LDs; hearing parents only

| Language(s) used with mother | Yes (%) | No (%) | n/r (%) | Additional deaf parent 'no' responses |
|------------------------------------|---------|--------|---------|---------------------------------------|
| spoken English only (n=18) | 27.8 | 66.7 | 5.6 | plus 1 |
| spoken English + some signs (n=11) | 45.5 | 54.5 | | |
| Sign (BSL) biling (n=7) | 14.3 | 85.7 | | plus 1 |

b) Difficulties with discursive interactions: profoundly deaf; group 1; not preschool; no LDs; hearing parents only

| Language(s) used with mother | yes | no | n/r | additional deaf parent 'no' responses |
|-----------------------------------|------|------|-----|---------------------------------------|
| spoken English only (n=9) | 33.3 | 66.7 | | plus 1 |
| spoken English + some signs (n=5) | 40 | 60 | | plus 1 |
| Sign (BSL) biling (n=5) | 20 | 60 | 20 | plus 3 |

c) Difficulties with discursive interactions: severely deaf; group 1; not preschool; no LDs; hearing parents only

| Language(s) used with mother | yes | no | no response | additional deaf parent 'no' responses |
|-----------------------------------|------|------|-------------|---------------------------------------|
| spoken English only (n=36) | 13.9 | 83.3 | 2.8 | plus 1 |
| other spoken languages (n=2) | 100 | | | |
| spoken English + some signs (n=7) | 42.9 | 28.6 | 28.6 | plus 1 |
| Sign (BSL) biling | | | | plus 2 |

Appendix 6

Nature of difficulties relating to deafness preventing discussion between deaf child (Group 1; school-age; no learning-related difficulties*) and parents who made explanatory comments (n=34)

| Hearing loss level of deaf child | Language(s)/languages modes used by mother with deaf child | Nature of barrier relating to deafness | No. of instances |
|--------------------------------------|--|---|------------------|
| Mild/unilateral/within normal limits | Spoken English | Sometimes reluctance to discuss - switches off hearing aids | 1 |
| | | Communication skills | 2 |
| | | Concentration issues | 1 |
| | Information not provided | Language/conceptual understanding (general) | 1 |
| Moderate | Spoken English | Language/conceptual understanding (general) | 1 |
| | | Language/conceptual understanding (homework issues) | 2 |
| | | More need for 1:1 | 1 |
| | Spoken English with limited signs | Extra time needed | 1 |
| | More than 1 spoken language | Language/conceptual understanding (general) | 1 |
| Severe | English | Language/conceptual understanding (general) + extra time needed | 2 |
| | | Language/conceptual understanding (transition issues) | 1 |
| | | More need for 1:1 | 1 |
| | English and gestures | Language/conceptual understanding (general) | 1 |
| | English + limited signing | Language/conceptual understanding (general) | 1 |
| | English + SSE | Communication skills | 1 |
| | | Reluctance to discuss, including homework | 1 |
| | More than 1 spoken language | Language/conceptual understanding (general) | 1 |
| | | Younger sibling helps with homework | 1 |

| | | | |
|------------------|-----------------------------|---|---|
| Profound | English | Needing to write things down | 1 |
| | | Language/conceptual understanding (more than two languages used) | 1 |
| | | Communication skills | 1 |
| | English and gestures | Language/conceptual understanding (general) | 1 |
| | English and limited signing | Language/conceptual understanding (general) + more time needed | 1 |
| | BSL and English | Language/conceptual understanding (more than one spoken language) | 1 |
| | Information not provided | Communication skills (depth of communication) | 1 |
| Cochlear implant | English | Language/conceptual understanding (general) | 2 |
| | | Language/conceptual understanding (vocabulary) | 1 |
| | | Communication skills | 1 |
| | English and gestures | Language/conceptual understanding (general) | 1 |
| | English and limited signing | Communication skills | 1 |
| | English and SSE/SE | Language/conceptual understanding (general) | 2 |
| | BSL and English | Language/conceptual understanding (mum's BSL vocabulary) | 1 |

*as defined in chart 4.4

Appendix 7

Text of questions relating to friendships

Part 6, questions 5&6 (referred to in this thesis as the 'Hearing Friendships Question')

Please tick one box to show which statement best fits your deaf child's friendships with **hearing** children:

☐ My deaf child has strong friendships with hearing children

Or

☐ My deaf child has limited friendships with hearing children.
Limitations **are not** related to their deafness.

Or

☐ My deaf child has limited friendships with hearing children. Limitations
are related to their deafness.

Or

☐ My deaf child has no friendships with hearing children.

Please give any further details you would like to provide about their relationships with hearing children.

Part 6, questions 7 & 8 (referred to in this thesis as the 'Deaf Friendships Question')

Please tick one box to show which statement best fits your deaf child's friendships with **deaf** children:

☐ My deaf child has strong friendships with other deaf children

Or

☐ My deaf child has limited friendships with other deaf children.

Or

☐ My deaf child has no friendships with other deaf children.

Please give any further details you would like to provide about their relationships with other deaf children.

Appendix 8

Text of 'Activities Question'

Does your child take part regularly in any activities outside of school hours?

☐ yes

☐ no

If yes, please indicate which kinds of activities (please tick as many boxes as necessary, and tick the right hand box if there are any difficulties which prevent your child from taking a full part).

Attends

Some difficulties

☐ 1 Local after-school hobby club

☐

☐ 2 Local after school sports club

☐

☐ 3 Specialist after-school club for deaf children/young people

☐

☐ 4 Local youth club attended by hearing young people

☐

☐ 5 Uniformed youth group such as Brownies, Scouts, Boys Brigade etc

☐

☐ 6 Specialist youth club for deaf children/young people

☐

☐ 7 Local Sports Club

☐

☐ 8 Other (please specify)

☐

If you have ticked to show that there are difficulties with your child's full participation, please give more details here

Activity no.

Comments

(5 tick boxes were provided)

(5 comment boxes were provided)

If your child does not take part, or has problems taking part, in any out of school activities, is this anything to do with their hearing loss?

☐ yes

☐ no

If yes, please give more details here:

Do you have any other comments about participation in out of school activities?

Appendix 9

Other types of activities attended by Group 1 school-age children with no learning-related difficulties* (n=65)

| Activity | No. children |
|---|--------------|
| after school activity | 2 |
| | 1 |
| various sports | 26 |
| various types of dance | 9 |
| various types of music | 7 |
| faith-based group | 1 |
| drama (including one group for deaf young people) | 3 |
| Duke of Edinburgh Award group | 1 |
| hobbies | 1 |
| homework club | 1 |
| library | 1 |
| BSL night class | 1 |
| organised activities from residential school | 1 |
| dance + music | 1 |
| sports + uniformed group | 1 |
| sports + dance (various) | 5 |
| music + Duke of Edinburgh award | 1 |
| sports + music + first aid | 1 |
| sports + music | 1 |
| Total | 65 |

*as defined in chart 4.4

Appendix 10

Categorisation of open comments relating to difficulties preventing full participation in structured activities outside of school.

The following list shows two examples of comments from each type of category.

Category 1: Communication problems – general:

‘People can’t understand him and he gets easily embarrassed’

‘Communication is always a problem, as are other children’s attitude to deafness.’

Category 2: Misses information/misunderstands:

‘Finds it very difficult - embarrassed as maybe cannot understand or hear what is being said...’

‘Misunderstands given instructions. Gets frustrated and annoyed with herself or person in charge.’

Category 3: Misses information/acoustic environment problematic:

‘Has difficulty in a large, noisy class following instructions’

‘Has actually stopped local youth club - said she found it hard to keep up with what was being said. This being due to the amount of background noise.’ (9)

Category 4: Communication in groups problematic:

‘Difficult to communicate in group situation. Other kids do not make allowances.’ (9)

‘Finds it hard to be part of a group - prefers one-to-one.’(9)

Category 5: Deaf awareness problems:

‘Attended Brownies but there were difficulties because of the attitude of the leader and her lack of deaf awareness.’ (5)

‘Leaders forget about kids in their classes who don’t hear as well. This leaves my daughter feeling confused and lost.’ (9)

Category 6: BSL access probs:

‘Communication of course. No one signs.’ (5)

‘To access benefits from clubs fully, X really needs sign support.’ (9)

Category 7: Language level problems:

‘Key worker used overly complex language.’ (5)

‘Has poor understanding for his age and other people don’t understand him.’ (9)

Category 8: Communication with peers problematic:

‘Other children with no difficulty can’t relate to my son.’

‘Although she loves going, she says other children can be cheeky sometimes & not understand her. That’s why she feels hesitant.’

Category 9: Isolation:

‘The reason so few clubs is that he feels isolated.’

‘She feels “odd one out” or awkward about missing things/not picking up things correctly.’

Category 10: Confidence/anxiety issues:

‘Lacks confidence when with his own age group he has been bullied at some clubs. Also no groups for hard of hearing children in area - running regularly.’

‘Anxiety about being different & possibly not being able to communicate.’

Category 11: Transport:

‘Problem with transport to attend after school clubs as school not local.’ (10)

‘Transport problems.’

Category 12: Attends school outwith locality:

‘He can’t participate in after school activities because school too far from home not in local area. School Taxi transport.’ (10)

‘Daughter less aware of activities and clubs due to fact she travels to school by taxi less opp. to mix’(10)

Category 13: Other issues:

‘Mum wants children to be in a safe environment and one that is compatible with their cultural and religious background. Not too keen on deaf clubs.’ (10)

‘Balance problems.’

Category 14: Problem may or may not be deafness:

‘Difficult to tell whether non-participation is related to hearing difficulties.’ (10)

‘X does not like to take part in after school activities. It is possible that his hearing loss is a factor.’ (10)

Category 15: Problem being resolved:

‘Has recently joined army cadets where they shout out orders, but that is being resolved.’ (5)

‘All hearing groups. Swimming lessons can be difficult as my son can’t wear his H aids in the water. We had to change to a different swimming centre but his current pool are very understanding and make sure X is given face-to-face contact.’

Appendix 11

Instances of types of difficulty preventing deaf children's full participation in structured mainstream activities (Group 1; school age; no learning-related difficulties*)

| Type of difficulty | Mild/unilat/ WNL*** (n=5 CYP**) | Moderate (n=20 CYP**) | | Severe (n=18 CYP**) | | Profound (n=14 CYP**) | | Cochlear implant (n=15 CYP**) | | Total no. |
|---|--|-----------------------------|------------|---------------------------|------------|-----------------------------|------------|-------------------------------------|------------|--------------|
| | n | n | % | n | % | n | % | n | % | |
| Communication probs- general [cat 1] | | 0 | 0 | 8 | 22 | 4 | 18 | 3 | 12 | 17 |
| misses info/misunderstands [cat 2] | 3 | 8 | 31 | 9 | 25 | 2 | 9 | 3 | 12 | 25 |
| misses info/acoustic environment probs [cat 3] | | 5 | 19 | 5 | 14 | 1 | 5 | 3 | 12 | 14 |
| communication in groups problematic [cat 4] | 2 | 2 | 7 | 1 | 3 | 1 | 5 | 1 | 4 | 7 |
| deaf awareness probs [cat 5] | | 2 | 7 | 3 | 8 | 2 | 9 | 5 | 19 | 12 |
| BSL access probs [cat 6] | | | | 1 | 3 | 1 | 5 | 2 | 8 | 4 |
| peer group communication/attitude probs [cat 7] | | 3 | 11 | 3 | 8 | 2 | 9 | 1 | 4 | 9 |
| language level problematic [cat 8] | | 1 | 4 | | | | | 1 | 4 | 2 |
| isolation [cat 9] | | 4 | 15 | 3 | 8 | 3 | 14 | 3 | 12 | 13 |
| confidence/anxiety issues [cat 10] | 1 | 2 | 7 | 3 | 8 | 6 | 27 | 4 | 15 | 16 |
| Totals | 6 | 27 | 100 | 36 | 100 | 22 | 100 | 26 | 100 | |

* as defined in chart 4.4

** children and young people

*** within normal limits

Appendix 12

Text of Cultural Activities Question

Part 8, questions 5 and 6

On a scale from 1 (frequently) to 3 (never), has your deaf child taken part in the following activities during the past 3 months?

Going to:-

| | 1 | 2 | n/a 3 | |
|--|---|---|----------|--------------------------|
| the cinema | 1 | 2 | 3 | <input type="checkbox"/> |
| a concert (including pop concerts) | 1 | 2 | 3 | <input type="checkbox"/> |
| watch live sporting events (eg football) | 1 | 2 | 3 | <input type="checkbox"/> |
| an exhibition, gallery or museum | 1 | 2 | 3 | <input type="checkbox"/> |
| a church, mosque or other place of worship | 1 | 2 | 3 | <input type="checkbox"/> |
| other activities of importance | 1 | 2 | 3 | <input type="checkbox"/> |

Are there any difficulties relating to their deafness which prevent them from doing any of these?

☐ yes

☐ no

If yes, please give brief details:

Appendix 13

Attendance of deaf children at cultural events (Group 1; school age; no learning-related difficulties*), by household social class (n=233)**

| | Managerial/professional (n=105) | | | Intermediate (n=59) | | | Working (n=36) | | | Unclassified (n=33) | | |
|---------------------------------|------------------------------------|-----------------|---------------|------------------------|-----------------|---------------|-------------------|-----------------|---------------|------------------------|-----------------|---------------|
| | % attends | % never attends | % no response | % attends | % never attends | % no response | % attends | % never attends | % no response | % attends | % never attends | % no response |
| cinema | 90 | 8 | 2 | 86 | 7 | 7 | 78 | 17 | 6 | 45 | 24 | 30 |
| concert | 34 | 40 | 26 | 20 | 53 | 27 | 33 | 47 | 19 | 9 | 45 | 45 |
| watching live sport | 48 | 42 | 10 | 51 | 39 | 10 | 44 | 33 | 22 | 42 | 15 | 42 |
| exhibitions, galleries, museums | 68 | 25 | 8 | 49 | 39 | 12 | 50 | 44 | 6 | 30 | 33 | 36 |
| place of religious worship | 51 | 37 | 11 | 44 | 46 | 10 | 47 | 47 | 6 | 21 | 42 | 36 |
| other | 65 | 6 | 30 | 54 | 12 | 34 | 42 | 28 | 31 | 48 | 15 | 36 |

* as defined in chart 4.4

** by Standard Occupational Categories

Appendix 14

Instances of types of comments about deaf children's difficulties participating in cultural activities (Group 1; school age; no learning-related difficulties*)

| | hearing loss level | | | | | first language | | | total no |
|---------------------------------|-----------------------|-----|--------|--------|---------------------|----------------|------------------------|-------------------|----------|
| | mild/unilat/ WNL** | mod | severe | profnd | cochlear implant | English | other spkn langs | BSL or BSL/Eng | |
| audition probs | 2 | 9 | 7 | 1 | 0 | 19 | 0 | 0 | 19 |
| subtitling probs | 0 | 2 | 4 | 6 | 7 | 9 | 2 | 8 | 18 |
| BSL access probs | 0 | 0 | 2 | 2 | 2 | 1 | 0 | 5 | 6 |
| can't follow what's going on | 1 | 4 | 1 | 5 | 6 | 12 | 0 | 5 | 17 |
| general c'cation probs | 0 | 0 | 3 | 3 | 1 | 3 | 0 | 4 | 7 |
| safety/dependency probs | 0 | 2 | 2 | 1 | 0 | 2 | 1 | 2 | 5 |
| misc | 0 | 1 | 1 | 2 | 2 | 4 | 2 | | 6 |

* as defined in chart 4.4

** within normal limits

Appendix 15

Text of Independence Question

On a scale from 1 (always) to 3 (never), how often do you:

Expect [your child] to do jobs around the home 1 ☐ 2 ☐ 3 ☐ n/a ☐

Allow [your child] to earn money (eg paper round) 1 ☐ 2 ☐ 3 ☐ n/a ☐

Allow [your child] to go out by themselves (eg visit friends, go to the shops etc)
1 ☐ 2 ☐ 3 ☐ n/a ☐

Allow [your child] to travel alone by public transport
1 ☐ 2 ☐ 3 ☐ n/a ☐

Are there any difficulties related to their deafness which prevents them from doing any of these?

☐ yes


☐ no


If yes, please give brief details:


Appendix 16

Family Survey Questionnaire (full version)

Family questionnaire 2004



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The University of Edinburgh

 NDCS
THE NATIONAL
DEAF CHILDREN'S
SOCIETY

Please complete and return this confidential questionnaire about your deaf child. You will be helping us provide accurate information about deaf children in Scotland. Your questionnaire will inform national and local decisions about education.

Confidentiality

The information provided is completely confidential and no children or families will be identified in any published materials. ADPS is securely within the Data Protection Act regulations for the safekeeping of information on the database.

Even if you do not wish to give the name of your child, please do still complete the questionnaire.

Words we use in the questionnaire

- 1 We use the term **child** all the way through the form, no matter what the age of your daughter or son.
- 2 When we talk about **home**, we are talking about the **main** place of residence of your deaf child.
- 3 We realise that not everyone completing this form will be the birth parents of the deaf child. For example you may be a step-parent or a foster parent, but for simplicity we use the terms **parents**, **mother** and **father** to refer to all parents/carers with parental responsibility for the child.
- 4 Similarly, when we refer to **brothers** and **sisters** we are including step and foster brothers and sisters etc.
- 5 The word **deaf** is used to refer to all levels of hearing loss, from mild to profound.

Questions on ethnic background, language and faith

We have included these questions because we believe it is important to take them into account when we are producing statistics. We have taken advice from the Minority Ethnic Learning Disability Initiative (MELDI) in Scotland.

Completed questionnaires

Please return your completed questionnaire in the freepost envelope provided.

Section 1 Personal details**Identity of the person who is completing this form**

Please tick one of the following boxes to show what your relationship is to the deaf child in the family.

- ☐ Mother
☐ Father
☐ Other (please give details)

Part 1 Identity and social context of the deaf child

- 1 Name or initials of deaf child

- 2 Date of birth ____ / ____ / ____

- 3 Gender

- ☐ Male
☐ Female

- 4 Home postcode

- 5 Please describe the ethnic background of your deaf child.
 Use whichever term or terms you feel most comfortable with. You may wish to give a specific race or group, such as African, Gypsy Traveller, Irish, Pakistani. You may wish to use a broader term, such as Scottish, White Scottish, Asian Scottish, Black Scottish, etc.

- 6 What is the **first** language of your deaf child, eg English, BSL, Arabic, Gaelic, Punjabi, etc? If your deaf child is bilingual, please name both languages.

- 7 What is the faith/religion, if any, of your deaf child?

Part 2 General family information

- 1 Please tick a box to show how many **hearing** parents presently live with your deaf child.

- ☐ None
☐ 1
☐ 2

- 2 Please tick a box to show how many **deaf** parents presently live with your deaf child.

- ☐ None
☐ 1
☐ 2

- 3 Does your child split their time between two separate homes? (eg if you are divorced/separated)

- ☐ Yes
☐ No

- 4 How many hearing brothers and sisters live at home with your deaf child?

Number of brothers/sisters ____

- 5 How many deaf brothers and sisters live at home with your deaf child?

Number of brothers/sisters ____

- 6 Please give the ages of all your children at home, including your deaf child, starting with the oldest.

Oldest child at home ____

Next oldest child at home ____

Next oldest child at home ____

Next oldest child at home ____

Next oldest child at home ____

Next oldest child at home ____

Next oldest child at home ____

Part 3**Information about your deaf child****1a** When did your child become deaf?

(Please tick one box)

- ☐ During mother's pregnancy/genetic
☐ Between birth and 6 weeks
☐ Sometime before 6 weeks (unsure when)
☐ 6 weeks-6 months
☐ 7-11 months
☐ 12-24 months
☐ Over 2 years
☐ Not known/unsure

1b If known, at what exact age did your child become deaf? (yy/mm) ____ / ____**2** When was your child diagnosed as deaf? (please give the age of the child **or** date of diagnosis)

- ☐ Age at diagnosis (yy/mm) ____ / ____
or
☐ if neonatal (days) ____

or

- ☐ Date of diagnosis ____ / ____ / ____
☐ Not known/unsure

3 What was the cause of your child's deafness?

- ☐ Not known, even after investigation
☐ Not known, not investigated

4 Please list any **diagnosed** visual impairments, medical conditions and specific learning difficulties experienced by your deaf child under **4a-d**:**4a** Diagnosed visual impairments

Name of condition (1)

- ☐ Not applicable
☐ Not known

(continued in the next column)

Level of condition

- ☐ Mild
☐ Moderate
☐ Severe

Diagnosed by (name of profession eg paediatrician, ophthalmologist etc)

Name of condition (2)

- ☐ Not applicable
☐ Not known

Level of condition

- ☐ Mild
☐ Moderate
☐ Severe

Diagnosed by (name of profession eg paediatrician, ophthalmologist etc)

4b Diagnosed medical conditions/physical disabilities

Name of condition (1)

- ☐ Not applicable
☐ Not known

Level of condition

- ☐ Mild
☐ Moderate
☐ Severe

Diagnosed by (name of profession eg paediatrician, ophthalmologist etc)

Name of condition (2)

- ☐ Not applicable
☐ Not known

Level of condition

- ☐ Mild
☐ Moderate
☐ Severe

Diagnosed by (name of profession eg
 paediatrician, ophthalmologist etc)

4c Diagnosed specific learning difficulty (eg
 autistic spectrum disorder; asperger's
 syndrome; attention deficit hyperactivity
 syndrome; dyslexia; social emotional and
 behavioural difficulties; dyspraxia)

Name of condition (1)

- ☐ Not applicable
☐ Not known

Level of condition

- ☐ Mild
☐ Moderate
☐ Severe

Diagnosed by (name of profession eg paedia-
 trician, ophthalmologist etc)

Name of condition (2)

- ☐ Not applicable
☐ Not known

(continued in the next column)

Level of condition

- ☐ Mild
☐ Moderate
☐ Severe

Diagnosed by (name of profession eg
 paediatrician, ophthalmologist etc)

4d Any comments about physical and learning
 disabilities?

Part 4**Information about
language and communi-
cation in the home**

For **all** of the following questions we are re-
 ferring to languages such as English (spoken
 or Sign Supported English), Gaelic, BSL,
 Urdu, etc.

1a What is the main language used at home
 within the family?

If the family uses two languages equally,
 please write them both here.

1b What other languages are used at home
 within the family?

- 2 What language(s) do you (**mother**) use with your deaf child? This can be completed directly by the person concerned or by the partner on their behalf.

Any comments?

- 3 What language(s) do you (**father**) use with your deaf child? This can be completed directly by the person concerned or by the partner on their behalf.

Any comments?

- 4 What language(s) do any **brothers and sisters** use with your deaf child?

☐ Not applicable

Any comments?

- 5 What language(s) do any **grandparents** use with your deaf child?

☐ Not applicable

(continued in the next column)

Any comments?

- 6 Do you have any comments about languages used between other family members and your deaf child?

We would like to share the information in Section 1 **in confidence** with the teacher(s) of deaf children who work(s) with your deaf child. This is to double-check that these basic details are correctly recorded in your child's file at school/visiting service. It will never be possible to identify your child or family from any information we publish.

Please tick one of the boxes to let us know whether we can share this information or not:

☐ Section 1 information **can be shared** with my child's teacher(s) of deaf children.*

or

☐ **Do not share** Section 1 information with my child's teacher(s) of deaf children.

* Please make sure you have completed questions 1 and 2 (page 3).

Section 2 Your child's education

In section 2, we appreciate that the information we are asking you to share with us is very personal. It will, therefore be treated as highly confidential and will not be made available to any person outside of the project team. No member of your family or yourself will be identified in any publication or report about our work.

The information will help us build up a picture of how parents value the specialist services provided for deaf children and their families across Scotland.

- 1 On a scale from 1 (very well) to 5 (not well at all), how well does your deaf child communicate with each family member? Please circle one number for each line.

| | | |
|--|-----------|--------------------------|
| (n/a = not applicable) | | n/a |
| Mother | 1 2 3 4 5 | <input type="checkbox"/> |
| Father | 1 2 3 4 5 | <input type="checkbox"/> |
| Brothers and sisters | 1 2 3 4 5 | <input type="checkbox"/> |
| Other adults (eg, uncle, grandparent) | 1 2 3 4 5 | <input type="checkbox"/> |
| Children/young people (eg, cousin, niece) | 1 2 3 4 5 | <input type="checkbox"/> |

Any other comments about communication with family?

Part 5 Information about school placement and specialist services

If your child is pre-school, please go straight to question 9 (page 8).

- 1 What level of school does your deaf child attend?
- ☐ Primary
- ☐ Secondary

- 2 Which of the following were you offered when you had to decide where to place your deaf child in their present school placement:

- ☐ Mainstream school with in-class specialist support (eg HI visiting teacher)
- ☐ Mainstream school with no in-class specialist support
- ☐ Mainstream school with HI/deaf unit
- ☐ School for deaf children
- ☐ Other (If other, please specify)

- 3 Which of the following best describes your deaf child's present school placement: (please tick one)

- ☐ Mainstream school with in-class specialist support (eg HI visiting teacher)
- ☐ Mainstream school with no in-class specialist support
- ☐ Mainstream school with HI/deaf unit
- ☐ School for deaf children
- ☐ Other (If other, please specify)

- 4 Are you now happy with your deaf child's present school placement?

- ☐ Yes
- ☐ No

- If yes, go to question 6.
- If no, can you explain briefly why you are not happy?

- 5 Did you officially contest the school placement decision? (please tick one)

- ☐ Yes, we officially contested the decision.
- ☐ No, we did not officially contest the decision.

6 Is your deaf child happy with their present school placement?

- ☐ Yes
☐ No

pupil - happy - plac

• If no, can you explain briefly why they are not happy?

pupil - not - happy - comment

7 Have you any other comments about your deaf child's **current** school placement?

current - placement - comments

8 Have you any comments to make about **previous** school placements?

9 Have you, as parents, had any direct contact with specialist services in the last 12 months (including meetings you may have chosen to have at school rather than home)?

- ☐ Yes
☐ No

• If yes, with whom? Tick as many boxes as appropriate, and write in approximately how many hours per month.

- ☐ Teacher of the deaf _____
☐ Cochlear implant team member _____
☐ Educational audiologist _____
☐ Speech and language therapist _____
☐ Educational psychologist _____
☐ Deaf support worker _____
☐ Support worker from Deaf Children's Society _____
☐ Social worker with deaf people _____

(continued in the next column)

- ☐ Bilingual key worker _____
☐ Advocate _____
☐ Other _____

(If **other**, please specify)

10 Do you have any comments about services provided?

11 If you have had no contact with some of these specialists, would you like to have done?

- ☐ Yes
☐ No
☐ Don't know

• If yes, who?

• Why?

12 On a scale from 1 (**very much support**) to 5 (**very little support**), how much support did you get from key people around the time that deafness was diagnosed?

Please circle one number for each line.

(n/a = not applicable)

| | 1 | 2 | 3 | 4 | 5 | n/a |
|-------------------------------|---|---|---|---|---|--------------------------|
| Paediatrician | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |
| ENT consultant | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |
| Health visitor | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |
| Teacher of the deaf | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |
| Cochlear implant team member | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |
| Educational audiologist | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |
| Hospital audiologist | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |
| Speech and language therapist | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |
| Educational psychologist | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |
| Deaf support worker | 1 | 2 | 3 | 4 | 5 | <input type="checkbox"/> |

(continued on the next page)

Social Worker with deaf people 1 2 3 4 5 ☐

Bilingual key worker 1 2 3 4 5 ☐

Advocate 1 2 3 4 5 ☐

Volunteer from Deaf Children's Society 1 2 3 4 5 ☐

Deaf volunteer (eg from Deaf Society) 1 2 3 4 5 ☐

One of your own friends 1 2 3 4 5 ☐

One of your own family 1 2 3 4 5 ☐

Other 1 2 3 4 5 ☐

(If **other**, please specify)

13 Would you have wished to receive support at that time from any of the persons listed above, from whom you did not receive support?

- ☐ Yes
☐ No
☐ Don't know

• If yes, who?

• Why?

• If your child is pre-school age, please go to question **18** (page 10).

14 On a scale from **1 (very much support)** to **5 (very little support)**, how much support did you get from key people when your child was at **primary** school?

Please circle one number for each line.

(n/a = not applicable)

| | | |
|------------------------------|-----------|--------------------------|
| Paediatrician | 1 2 3 4 5 | <input type="checkbox"/> |
| ENT consultant | 1 2 3 4 5 | <input type="checkbox"/> |
| Health visitor | 1 2 3 4 5 | <input type="checkbox"/> |
| Teacher of the deaf | 1 2 3 4 5 | <input type="checkbox"/> |
| Cochlear implant team member | 1 2 3 4 5 | <input type="checkbox"/> |

(continued in the next column)

Educational audiologist 1 2 3 4 5 ☐

Hospital audiologist 1 2 3 4 5 ☐

Speech and language therapist 1 2 3 4 5 ☐

Educational psychologist 1 2 3 4 5 ☐

Deaf support worker 1 2 3 4 5 ☐

Social Worker with deaf people 1 2 3 4 5 ☐

Bilingual key worker 1 2 3 4 5 ☐

Advocate 1 2 3 4 5 ☐

Volunteer from Deaf Children's Society 1 2 3 4 5 ☐

Deaf volunteer (eg from Deaf Society) 1 2 3 4 5 ☐

One of your own friends 1 2 3 4 5 ☐

One of your own family 1 2 3 4 5 ☐

Other 1 2 3 4 5 ☐

(If **other**, please specify)

15 Would you have wished to receive support at that time from any of the persons listed above, from whom you did not receive support?

- ☐ Yes
☐ No
☐ Don't know

• If yes, who?

• Why?

• If your child is primary age, please go to question **18** (page 10).

16 On a scale from **1 (very much support)** to **5 (very little support)**, how much support did you get from key people when your child was at **secondary** school?

Please circle one number for each line.

(n/a = not applicable)

n/a

- | | | |
|--|-----------|--------------------------|
| Paediatrician | 1 2 3 4 5 | <input type="checkbox"/> |
| ENT consultant | 1 2 3 4 5 | <input type="checkbox"/> |
| Health visitor | 1 2 3 4 5 | <input type="checkbox"/> |
| Teacher of the deaf | 1 2 3 4 5 | <input type="checkbox"/> |
| Cochlear implant team member | 1 2 3 4 5 | <input type="checkbox"/> |
| Educational audiologist | 1 2 3 4 5 | <input type="checkbox"/> |
| Hospital audiologist | 1 2 3 4 5 | <input type="checkbox"/> |
| Speech and language therapist | 1 2 3 4 5 | <input type="checkbox"/> |
| Educational psychologist | 1 2 3 4 5 | <input type="checkbox"/> |
| Deaf support worker | 1 2 3 4 5 | <input type="checkbox"/> |
| Social Worker with deaf people | 1 2 3 4 5 | <input type="checkbox"/> |
| Bilingual key worker | 1 2 3 4 5 | <input type="checkbox"/> |
| Advocate | 1 2 3 4 5 | <input type="checkbox"/> |
| Volunteer from Deaf Children's Society | 1 2 3 4 5 | <input type="checkbox"/> |
| Deaf volunteer (eg from Deaf Society) | 1 2 3 4 5 | <input type="checkbox"/> |
| One of your own friends | 1 2 3 4 5 | <input type="checkbox"/> |
| One of your own family | 1 2 3 4 5 | <input type="checkbox"/> |
| Other | 1 2 3 4 5 | <input type="checkbox"/> |

(If other, please specify)

17 Would you have wished to receive support at that time from any of the persons listed above, from whom you did not receive support?

- ☐ Yes
☐ No
☐ Don't know

• If yes, who?

• Why?

18 Any overall comments about the services which have been provided?

19 Are any other services currently provided to you as a family by specialist deaf education services? (eg by deaf school, HI Unit or hearing-impaired visiting service)

- ☐ Parent and toddler group
☐ Parents' group meetings
☐ BSL classes
☐ Other (please specify)

20 Do you know about the National Deaf Children's Society (NDCS)?

- ☐ Yes
☐ No

• If no, would you like us to send you some information?

- ☐ Yes
☐ No

• If you would like us to send you information, please give us an address for posting:

Postcode:

21 If you already know about NDCS, who gave you initial information about it? (please tick **one** box only)

- ☐ Teacher of the deaf
☐ Cochlear implant team member
☐ Educational audiologist
☐ Speech and language therapist
☐ Educational psychologist
☐ Deaf support worker

(continued on the next page)

- ☐ Social worker with deaf people
☐ Bilingual key worker
☐ Advocate
☐ Another parent of deaf children
☐ Volunteer from Deaf Children's Society
☐ Deaf volunteer (eg from Deaf Society)
☐ One of your own friends
☐ One of your own family
☐ Other (please specify)

Part 6 Information about your child's personal and social development

These questions are for school pupils only. If your deaf child is pre-school age, please go straight to Section 3 (page 13).

- 1 Does your deaf child take part **regularly** in any activities out of school hours?

- ☐ Yes
☐ No

• If yes, please indicate which kinds of activities (please tick as many boxes as necessary, and tick the right hand box if there are any difficulties which prevent your child from taking a full part).

- | attends | some difficulties |
|--|--------------------------|
| <input type="checkbox"/> 1 Local after-school hobby club | <input type="checkbox"/> |
| <input type="checkbox"/> 2 Local after-school sports club | <input type="checkbox"/> |
| <input type="checkbox"/> 3 Specialist after-school club for deaf children/young people | <input type="checkbox"/> |
| <input type="checkbox"/> 4 Local youth club attended by hearing young people | <input type="checkbox"/> |
| <input type="checkbox"/> 5 Uniformed youth groups such as Brownies, Scouts, Boys Brigade etc | <input type="checkbox"/> |
| <input type="checkbox"/> 6 Specialist youth club for deaf children/young people | <input type="checkbox"/> |
| <input type="checkbox"/> 7 Local sports club | <input type="checkbox"/> |
| <input type="checkbox"/> 8 Other (please specify) | <input type="checkbox"/> |

- 2 If you **have** ticked to show that there are difficulties with your child's full participation, please give more details here:

activity no. comment

| | |
|--|--|
| | |
| | |
| | |
| | |
| | |

- 3 If your child does not take part, or has problems taking part, in any out of school activities, is this anything to do with their hearing loss?

- ☐ Yes
☐ No

• If yes, please give more details here:

| |
|--|
| |
|--|

- 4 Do you have any other comments about participation in out of school activities?

| |
|--|
| |
|--|

The next questions will give us information about friendship patterns among deaf children.

- 5 Please tick one box to show which statement best fits your deaf child's friendships with **hearing** children.

☐ My deaf child has strong friendships with hearing children.

or

☐ My deaf child has limited friendships with hearing children. Limitations **are not** related to their deafness.

or

☐ My deaf child has limited friendships with hearing children. Limitations **are** related to their deafness.

or

☐ My deaf child has no friendships with hearing children.

- 6 Please give any further details you would like to provide about their relationships with hearing children.

- 7 Please tick one box to show which statement best fits your deaf child's friendships with other **deaf** children.

☐ My deaf child has strong friendships with other deaf children.

or

☐ My deaf child has limited friendships with other deaf children.

or

☐ My deaf child has no friendships with other deaf children.

- 8 Please give any further details you would like to provide about their relationships with other deaf children.

- 9 Does your deaf child have homework to do?

☐ Yes

☐ No

• If yes, on average, how many hours per week (in term time) does your deaf child spend on homework?

☐ _____ hours per week

☐ Not known

☐ Not applicable

- 10 Any comments you would like to make about homework?

Section 3

Information about you

In section 3, we appreciate that the information we are asking you to share with us is very personal. **It will be treated as highly confidential** and will not be made available to any person outside of the project team. No member of your family or yourself will be identified in any publication or report about our work.

Information about your situation (as opposed to that of your deaf child) is requested so that we can compare the situation of parents of deaf children with that of the general population in Scotland (eg information on income, educational background, employment etc.).

Part 7

Income and occupation of parents

- 1 What is your total household income before taxation? (please tick one box)

- ☐ less than £6,000 per year 1
☐ £6,001-£11,000 per year 2
☐ £11,001-£16,000 per year 3
☐ £16,001-£21,000 per year 4
☐ £21,001-£26,000 per year 5
☐ £26,001-£31,000 per year 6
☐ over £31,000 per year 7

- 2 Please indicate the occupation of parents who live at home at this time (please tick one box for each parent).

father mother

- 1 Working full time (30 hours a week or more) ☐ ☐
 2 Working part time ☐ ☐
 3 Doing full time unpaid work at home (eg looking after children) ☐ ☐
 4 Retired ☐ ☐
 5 Unable to work because of illness or disability ☐ ☐

(continued in the next column)

- 6 Unemployed ☐ ☐
 7 Being a full-time student ☐ ☐
 8 Being a part-time student ☐ ☐
 9 Doing something else (please specify) ☐ ☐

father

mother

- 3 Please indicate the occupation of each parent living at home at the moment. If not currently working outside of the home, please write down the most recent job.

3a Name of father's job

What kind of work is involved in the job?

What kind of place or organisation? (eg shoe shop, electronics company, civil service)

3b Name of mother's job

What kind of work is involved in the job?

What kind of place or organisation? (eg shoe shop, electronics company, civil service)

- 4 Please indicate the **highest** level of qualification reached by each parent at home to date (please tick the highest level of qualification for each parent)

| | father | mother |
|--|--------------------------|--------------------------|
| 0 No qualifications | <input type="checkbox"/> | <input type="checkbox"/> |
| 1 CSEs, O-Grades/Levels, Standard Grades, SCOTVEC modules etc. | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 Highers or A-Levels | <input type="checkbox"/> | <input type="checkbox"/> |
| 3 HNC, HND, RGN, teaching diploma etc. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4 Degree or higher degree | <input type="checkbox"/> | <input type="checkbox"/> |
| 5 Other (please specify) | <input type="checkbox"/> | <input type="checkbox"/> |
| father | | |
| mother | | |

Part 8 Family activities

In the following questions, 'Not applicable' (n/a) is appropriate if, for example, your deaf child is too young for you to be able to answer the question.

- 1 On a scale from 1 (**always**) to 3 (**never**), how often are you able to do these things with your deaf child:

| | 1 | 2 | 3 | n/a |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| Discuss with them the day's events (eg at school/nursery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Support them in doing their homework | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Discuss with them their own interests | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- 2 Are there any difficulties related to their deafness which prevent any of these interactions?

- ☐ Yes
☐ No

• If yes, please give brief details:

- 3 On a scale from 1 (**always**) to 3 (**never**), how often do you:

| | 1 | 2 | 3 | n/a |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| Expect them to do jobs around the home | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Allow them to earn money (eg paper round) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Allow them to go out by themselves (eg visit friends, go to the shops etc) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Allow them to travel alone by public transport | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- 4 Are there any difficulties related to their deafness which prevents them from doing any of these?

- ☐ Yes
☐ No

• If yes, please give brief details:

- 5 On a scale from 1 (**frequently**) to 3 (**never**), has your deaf child taken part in the following activities during the past 3 months?

| | 1 | 2 | 3 | n/a |
|--------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Reading | | | | |
| a book | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| a newspaper | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| a magazine | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| a comic | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Using a mobile phone | | | | |
| for voice calls | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| for text and/or email messages | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Using a computer | | | | |
| for email | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| for internet access | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

(continued on the next page)

| | |
|---|--|
| <p>Going to-</p> <p>the cinema 1 2 3 <input type="checkbox"/></p> <p>a concert (including pop concerts) 1 2 3 <input type="checkbox"/></p> <p>watch live sporting events (eg football) 1 2 3 <input type="checkbox"/></p> <p>an exhibition, gallery or museum 1 2 3 <input type="checkbox"/></p> <p>a church, mosque or other place of worship 1 2 3 <input type="checkbox"/></p> <p>other activities of importance 1 2 3 <input type="checkbox"/></p> | <p>n/a</p> <p>9 If your deaf child watches programmes that are neither subtitled nor interpreted, how does your child access them? (please tick all that apply).</p> <p><input type="checkbox"/> Attempts to lipread persons speaking</p> <p><input type="checkbox"/> Turns up the sound</p> <p><input type="checkbox"/> Uses amplification equipment (eg loop system, infra-red system etc)</p> <p><input type="checkbox"/> Asks hearing person to interpret into BSL</p> <p><input type="checkbox"/> Asks hearing person to speak/lipspeak</p> <p><input type="checkbox"/> Other (please specify)</p> <p><input type="checkbox"/> Does not access what is spoken; just watches the programmes</p> |
| <p>6 Are there any difficulties related to their deafness which prevents them from doing any of these?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p>• If yes, please give brief details:</p> <div style="border: 1px solid black; height: 60px; width: 100%;"></div> | <p>10 Please write any other information you think might be relevant in relation to your deaf child.</p> <div style="border: 1px solid black; height: 150px; width: 100%;"></div> |
| <p>7 On average, how many hours per week does your deaf child watch television?</p> <p>___ hours</p> | |
| <p>8 On a scale from 1 (frequently) to 3 (never), how often does your deaf child watch television programmes that are:</p> <p style="text-align: right;">n/a</p> <p>For deaf children/young people (eg 'Switch') 1 2 3 <input type="checkbox"/></p> <p>Interpreted into British Sign Language 1 2 3 <input type="checkbox"/></p> <p>Subtitled 1 2 3 <input type="checkbox"/></p> <p>Neither subtitled nor interpreted 1 2 3 <input type="checkbox"/></p> | |

Thank you very much for taking the time to complete this questionnaire. Please return it to us in the freepost envelope (no stamp needed).

Address

Achievements of Deaf Pupils in Scotland
Simon Laurie House
Moray House School of Education
The University of Edinburgh
Holyrood Road
FREEPOST SC0 6671
Edinburgh EH8 0BR

